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Pepperdine University
Graduate School of Education and Psychology

PATIENTS' PERSPECTIVES ON EATING DISORDER TREATMENT:
A RESOURCE FOR PRACTITIONERS

A clinical dissertation submitted in partial satisfaction
of the requirements for the degree of
Doctor of Psychology

by

Danielle L. Davis

July, 2010

Barbara Ingram, Ph.D. – Dissertation Chairperson

This clinical dissertation, written by

Danielle L. Davis

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

Barbara Ingram, Ph.D., Chairperson

Anat Cohen, Ph.D.

Gitu Bhatia, Psy.D.

Robert A. deMayo, Ph.D., ABPP
Associate Dean

Margaret J. Weber, Ph.D.
Dean

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DEDICATION

This dissertation is dedicated to all those who have suffered from an eating disorder. Thank you to the ones who shared your story and, therefore, made this project possible. Your voices are heard.

ACKNOWLEDGEMENTS

This dissertation, and my doctoral work as a whole, would not have been possible without the support, encouragement, love and guidance that I received from many people. First and foremost, I must express my gratitude to Dr. Ingram, my chairperson, for her commitment to making this project a success. Dr. Ingram, thank you for showing interest and enthusiasm in my project since day one. I will also always remember how you treated me like a person and not just a student. I feel honored and fortunate to have worked with someone who is so passionate about helping students succeed. To my other committee members: Dr. Cohen, you have been there since the beginning. I remember when I first met you for my interview. I knew then that I could learn so much from you. You have always been there for me and encouraged me in the toughest of times. It has been such a rewarding past year with you at the clinic and I will miss you dearly. Dr. Bhatia, I am so grateful that you chose to join my committee. Thank you for your calm, centered, and thoughtful way of being. I am especially grateful for your expertise in cultural diversity, which significantly contributed to this project. I will also never forget all of the positive feedback you gave me and how you encouraged me to disseminate my booklet.

I would also like to express my appreciation to Dr. Segal for being one of my greatest professional mentors. Dr. Segal, thank you for telling me that I was “talented” when I was not sure about my abilities. You have offered me countless opportunities. I am forever indebted to you for everything you have given me, including the hundreds of hours you have spent giving me your individual attention in supervision.

I must extend a special thank you to my parents for their unwavering dedication to giving me the best life they could. Mom, thank you for always telling me how proud you

were of me and for all the times you told me to trust myself. You are always in my heart. Dad, thank you for telling me as far back as I can remember that I could be anything I want to be and for always pushing me to continue in school. I will never forget your relentless commitment to doing whatever it takes for me to finish my education. Thank you also to my brother, Shaun, and my sister-in-law, Jaime, for always being a part of my life and for giving me the joy of being an aunt. Brooke, Cameron, and Chloe, you are so special to me. Thank you for making me smile and laugh when I needed nothing more.

I would also like to express my heartfelt gratitude to Christopher. Thank you for being my life witness. You have been there every step of the way. Thank you for always believing in me and understanding when I had nothing left to give. I am particularly grateful for all the times you nourished me with healthy, delicious dinners when I had no energy to cook. I will never forget the sacrifices you made over this past year, which allowed me to pursue my dream.

I must thank my laotong, Danielle. You have been my rock throughout these past five years. I will always remember the countless hours you spent listening to my struggles and triumphs. You understand me better than anyone. Thank you for telling me that the end would come when I needed to hear that the most. I am so fortunate to have you in my life and I look forward to growing old with you.

Finally, I would like to express my gratitude to E.R. for your patience, commitment, love, and generosity. Without you, I would not be here. I will always cherish the years that I spent with you. The lessons I learned are with me everyday. You will always be close to my heart.

VITA
Danielle L. Davis

EDUCATION

- Present Pepperdine University
Clinical Psychology Doctoral Program (APA-accredited)
Expected graduation date: August 2010
- 5/04 California Lutheran University, M.S., Clinical Psychology
- 4/01 Pepperdine University, B.A., Psychology
Magna Cum Laude

CLINICAL EXPERIENCE

- 8/09-Present University of North Carolina at Chapel Hill, Counseling and Wellness Services
Supervisors: Meredith Mayer, Ph.D. and Glen Martin, Ph.D. (Licensed Psychologists)

Pre-Doctoral Intern

- Conduct brief and long-term individual psychotherapy with a diverse population of university students
- Facilitate group psychotherapy
- Participate in triage teams and provide crisis services, including suicide assessment and intervention
- Specialization in eating disorders, including working within a multidisciplinary team, the *Eating Disorders Treatment Team*, and providing individual psychotherapy to students with eating disorders
- Create and provide outreach projects designed to target traditionally underserved or minority groups
- Evaluate students who have been brought to public attention and make recommendations to the *Emergency Evaluation and Action Committee* about the student's wellbeing and ability to safely remain in an academic setting
- Conduct academic interventions in order to assess how a student's mental health may be impacting his/her academic functioning and determine if a medical withdrawal or course underload would be appropriate
- Participate in multicultural mentoring and present multicultural case presentations throughout the training year

- Perform in-depth intake interviews and provide recommendations for treatment

6/06-6/07
and
5/08-7/09

Pepperdine Community Counseling Center, Encino CA
Supervisor: Anat Cohen, Ph.D. (Licensed Psychologist)

Clinic Therapist

- Provided outpatient cognitive-behavioral, brief dynamic, and longer-term insight-oriented dynamic psychotherapy to a wide range of clients including adults and couples suffering from mood and anxiety disorders, relational difficulties, and personality disorders
- Conducted psychotherapy with undergraduate and graduate students
- Implemented crisis interventions
- Acted as “on-call” therapist on a rotating basis
- Conducted intake assessments and diagnostic interviews
- Wrote integrative intake reports which include five axes diagnoses and treatment plans
- Presented clinical presentations in weekly individual and group supervision

7/07-7/09

Private Practice, Encino CA
Supervisor: Shelley Segal, Psy.D. (Licensed Psychologist)

Registered Psychological Assistant (PSB 32885)

- Provided adult outpatient psychotherapy
- Treatment plans were individualized based on the presenting problem and diagnosis and include psychodynamic and cognitive-behavioral modalities
- Typical clients suffered from mood and/or anxiety disorders and relational difficulties
- Recorded treatment progress in patient charts
- Collaborated with psychiatrists in the management of medication

7/07-4/08

Assessment Center at the Center for Autism and Related Disorders (CARD), Tarzana CA
Supervisor: Bahareh Talei, Psy.D. (Licensed Psychologist)

Assessor

- Administered, scored, and interpreted comprehensive psychological batteries
- Examples of diagnoses included: Pervasive Developmental Disorders, Mental Retardation, and ADHD

- Typical batteries included cognitive, language, social, and adaptive functioning tests
- Prepared integrative assessment reports with recommendations for appropriate treatment plans and diagnoses
- Participated in multidisciplinary treatment planning meetings and provided consultation
- Conducted feedback sessions with parents and treatment providers

12/02-4/08

Center for Autism and Related Disorders (CARD), Tarzana CA
Supervisor: Doreen Granpeesheh, Ph.D. (Licensed Psychologist)

Therapist (12/02-6/04)

- Initial position at CARD. Implemented one-to-one therapy programs for children and adolescents across a range of functioning at home and in the school setting
- Examples of diagnoses included: Pervasive Developmental Disorders, Mental Retardation, and ADHD
- Carried out the Behavior Intervention Plan (BIP) for such challenging behaviors as: tantruming, aggression, non-compliance, self-injury, stereotypical behaviors, pica, and echolalia
- Attended bi-monthly team meetings for each client in order to review progress and make program updates

Senior Therapist (6/04-8/05)

- Continued with all of the direct service responsibilities listed above
- Led therapy programs by providing ongoing training to therapists
- Many clients suffered from concurrent disorders including mood, anxiety, and feeding disorders
- Worked within the family system by providing parent support and training, and helping siblings cope and learn how to interact with their brother or sister
- Wrote a quarterly report on each client's progress
- Case load averaged 7 clients

Case Supervisor (8/05-4/08)

- Designed intensive, comprehensive and individualized therapy programs in order to decrease challenging behaviors and increase skill acquisition
- All therapy programs included a BIP designed following a functional assessment or functional analysis of each behavior
- Skill acquisition programs targeted a variety of domains, including but not limited to: language, play and social skills, social-cognition, self-help, and executive functioning
- Participated in Individualized Education Plan (IEP) meetings,

which included collaborating with school principals, classroom teachers, speech pathologists, psychiatrists and occupational therapists

- Provided training for teachers in the classroom
- Wrote progress reports to school districts and regional centers, including updates on specific goals and recommendations for future treatment
- Gained experience with augmentative communication systems, including: Picture Exchange Communication System (PECS) and an electronic communication system
- Trained two therapists to become Case Supervisors, including: reviewing all of their treatment plans, observing all of their team meetings, reading all of their internal and external reports, holding bi-monthly individual mentor meetings, and completing their quarterly evaluations
- Gained experience with over 40 children and adolescents with developmental disabilities from 12/02-4/08

SUPERVISION EXPERIENCE

9/08-7/09 Pepperdine Community Counseling Center, Encino CA
Supervisor: Anat Cohen, Ph.D. (Licensed Psychologist)

Peer Supervisor

- Supervised first-year doctoral students during their clinical training practicum
- Provided weekly individual supervision for peer supervisees to discuss therapy cases and enhance clinical training
- Participated in weekly group supervision of peer supervisors

RELATED WORK EXPERIENCE

5/08-7/09 Pepperdine Community Counseling Center, Encino CA
Supervisor: Anat Cohen, Ph.D. (Licensed Psychologist)

Graduate Assistant

- Conducted telephone intakes
- Screened and assign callers to clinic therapists
- Conducted chart audits
- Trained therapists on administering, scoring and interpreting clinic measures
- Served as liaison to the *Pepperdine Clinic Advancement and Research Committee*

- Participated in standardizing clinic procedures across all Pepperdine clinics
- Created and managed research files, including gathering informed consent and redacting identifying information
- Assisted the clinic director in conducting daily clinic business

RESEARCH EXPERIENCE

- 5/05-6/09 Doctoral Dissertation: *Patients' Perspectives on Eating Disorders Treatment: A Resource for Practitioners*
Chairperson: Barbara Ingram, Ph.D., Pepperdine University
- 2/02-5/03 Research Assistant: *Adaptive Coping with Terrorism*
Supervisor: Marylie Gerson, Ph.D., California Lutheran University
- Duties included literature searching, data organization, entry, and analysis. Intense work with SPSS
- 1/01-11/01 Research Proposal: *Implicit Attitudes of Interracial Couples*
Advisor: Khanh Bui, Ph.D., Pepperdine University
- Duties included literature searching, critically reviewing the literature, and preparing an IRB proposal
- 8/00-12/00 Research Assistant: *Exploring the Accuracies and Inaccuracies of Personality Perception Following Internet-Mediated Communication*
Supervisor: Steven Rouse, Ph.D., Pepperdine University
- Duties included explaining the study to participants, getting informed consent, and overseeing instrument completion and internet interactions

CONFERENCE PRESENTATIONS

- 5/03 Davis, D. L., Canavarro, T. C., & Rouse, V. S. (2003, May). *Self-monitoring and self-esteem: The independence of intuitively-related constructs*. Poster session presented at the annual meeting of the American Psychological Society, Atlanta, GA.

TEACHING EXPERIENCE

- 12/05 Workshop Presenter: *Using Applied Behavior Analysis to Teach Children with Autism: An Introduction for Parents*

- Provided a two-day workshop for parents of children with Autism and school staff members
- Day one consisted of a full day of lecture and day two consisted of hands on training

- 1/03-5/03 Teaching Assistant: *Psychological Testing and Assessment*
Professor: Leanne Neilson, Psy.D., California Lutheran University
- Prepared and presented three lectures, designed and graded quizzes
- 8/02-12/01 Teaching Assistant: *Introductory Statistics*
Professor: Douglas Saddler, Ph.D., California Lutheran University
- Tutor, lab assistant, and exam proctor
- 8/01-12/01 Teaching Assistant: *Introductory Psychology*
Professor: Cindy Miller-Perrin, Ph.D., Pepperdine University
- Graded exams and term papers
- 1/01-4/01 Teaching Assistant: *Physiological Psychology*
Professor: Cindy Miller-Perrin, Ph.D., Pepperdine University
- Prepared and presented two lectures in the laboratory setting, assisted at all laboratory sessions, designed study guides, held study sessions, and graded exams.

AWARDS AND SCHOLARSHIPS

Supervisor of the Year, Center for Autism and Related Disorders, 2007
 Supervisor-Trainee of the Year, Center for Autism and Related Disorders, 2005
 Therapist of the Quarter, Center for Autism and Related Disorders, 2003
 Travel Award, American Psychological Society, 2003
 Graduate Assistantship, California Lutheran University, 2001-2004
 Dean's Scholarship at Seaver College of Pepperdine, 1998-2001
 Robert Mantovani Scholarship Award for Scholastic Standing and Service, 1998
 Kathleen D. Loly Award for Academic Excellence and Community Service, 1998
 Kil Coster Scholarship Award, 1998
 Alpha Gamma Sigma Scholarship Award, 1997-1998

ABSTRACT

The need for improved treatment for patients with eating disorders is indicated from outcome studies and clinicians' reports. In order to understand the patient's motivation to engage actively in treatment, as well as the factors that contribute to successful outcome, it is important to attend to patients' perspectives on treatment. The author critically reviewed studies on patients' views and 10 key treatment elements were identified: the therapeutic relationship, provision of social support, collaborative treatment, focus on emotions, focus on underlying issues, inclusion of psychoeducation, therapist's knowledge of EDs, behavioral interventions, appropriate use of medication, and therapist's competence in family dynamics. Based on this review, a comprehensive 61-page resource booklet was created. The resource covers a broad range of topic areas, such as etiological theories, treatment modalities, and cultural diversity, while focusing on patients' views of what works and does not work in eating disorder treatment. This dissertation concludes with a discussion of the resource booklet, including strengths and limitations, along with suggestions for future research.

Chapter I: Introduction

Eating Disorders (EDs) can be devastating to the lives of people who suffer from them. They can affect all areas of an individual's functioning, including emotional well-being, social relationships, occupational functioning, and physical health. The National Eating Disorders Association (2006), which was founded in 2001, reported that in the United States as many as 10 million females and 1 million males are suffering from EDs. In addition, the number of individuals with EDs has been increasing since their recognition, paralleling society's growing obsession with being thin (Costin, 2007).

Clinicians often report that patients with EDs are difficult to treat (Kaplan & Garfinkel, 1999). In order to understand the patient's motivation to engage actively in treatment, as well as the factors that contribute to successful outcome, it is important to attend to patients' perspectives on treatment. In recent years, studies on patients' perspectives have been receiving greater attention, and clinicians would benefit from learning what researchers have learned about patients' needs and preferences. This dissertation focuses on what we have learned from patients about their experiences in ED treatment. A complete description of the purpose of this project is provided at the end of this chapter.

History of Eating Disorder Diagnoses

Eating disorders, once rare and little known clinical phenomena, are now disorders of troublesome prevalence that are gaining increased attention from the professional community. The first medical account of the condition known today as anorexia nervosa (AN) was described by the English physician Richard Morton in 1689 (Silverman, 1997). In his book, *Phthisiologia: Or a Treatise of Consumptions*, he referred

to a *nervous consumption* of the body caused by sadness and anxious cares (Costin, 2007; Silverman). However, Morton's case studies of both a girl and a boy did not attract any attention until being rediscovered three centuries later (Vandereycken, 2002a). Two prominent physicians, Ernest-Charles Lasègue of Paris and Sir William Gull of London must be awarded *joint parenthood* for the first explicit description of AN (Vandereycken). In 1873, Lasègue published an article, *On Hysterical Anorexia*, shortly before Gull presented his own case reports utilizing the term "anorexia nervosa" (Silverman). The symptoms described by Gull and Lasègue are still valid today: severe weight loss, amenorrhea, restlessness, and no evidence of underlying organic pathology (Vandereycken).

Although the French and British press showed some interest in the new syndrome, in many other countries, including the United States, AN remained a marginal phenomenon until well into the 20th century (Vandereycken, 2002a). In 1973, Hilde Bruch introduced the first major book in the field, *Eating Disorders: Obesity, Anorexia Nervosa, and the Person Within*. Bruch focused attention on the lack of self-esteem and the distorted body image of AN patients, which led to the addition of two features to the original clinical picture: the relentless pursuit of thinness and the characteristic disturbance of body image (Vandereycken). Later, in 1978, Bruch's pioneering book, *The Golden Cage: The Enigma of Anorexia Nervosa*, was published and raised awareness of EDs among the general public.

It was in the context of a growing interest in AN that the clinical syndrome of bulimia nervosa (BN) was recognized (Vandereycken, 2002a). Sporadic reports appeared about patients with compulsive overeating followed by self-induced vomiting

(Vandereycken). It is commonly known that the Romans engaged in binge eating and vomiting rituals, but bulimia was first described in medical terms in 1903 in *Obsessions et la Psychasthenie* by psychiatrist Pierre Janet (Costin, 2007). Janet described the case of a woman named Nadja who engaged in compulsive binges and compensatory behaviors. Later, in 1944, the Swiss psychiatrist Ludwig Binswanger published the most carefully documented case report on bulimia (Vandereycken). Then, in 1979, the British psychiatrist Gerald Russell coined the term “bulimia nervosa” (Vandereycken).

EDs were first included in The *Diagnostic and Statistical Manual of Mental Disorders (DSM), Third Edition* (1980). The *DSM, Fourth Edition, Text Revision* (2000), includes three diagnostic categories for EDs. Anorexia Nervosa (AN) is characterized by a refusal to maintain a minimally normal body weight and an intense fear of gaining weight or becoming fat. Bulimia Nervosa (BN) is characterized by repeated episodes of binge eating followed by compensatory behaviors to prevent weight gain. Eating Disorder Not Otherwise Specified (ED-NOS) includes disorders of eating that do not meet the criteria for AN or BN (e.g., Binge-Eating Disorder: BED).

Cultural Diversity

It is generally assumed that EDs are primarily a problem for young, white females; however, EDs are on the rise in various populations. The spectrum of body image and eating problems appears in every economic and ethnic stratum of American culture and in at least 40 countries worldwide, including India and Africa (Gordon, 2000). Lee and Katzman (2002) reported that AN and BN are becoming common clinical problems among young females and males in high-income Asian societies such as Japan,

Hong Kong, Singapore, Taiwan, and the Republic of Korea. They report that community studies in Hong Kong have indicated that 3-10% of young females suffer from EDs.

Numerous studies in the United States have investigated the prevalence of EDs in different ethnic groups. Racial differences in the distribution of EDs are reported throughout the literature, including the finding that bulimic symptoms are significantly less common among many minority groups (Lokken, Worthy, Ferraro, & Attman, 2008). Research indicates that BN is significantly less prevalent among black women than white women (Striegel-Moore et al., 2003). Lokken and colleagues (2008) found in a sample of college women that Southeastern black women reported significantly lower levels of BN symptoms than Northeastern white women, and they had lower levels of body image dissatisfaction than Northeastern and Southeastern white women. They also found that Southeastern black women were less likely to be aware of or endorse mainstream standards of appearance than the white women. However, some researchers have argued that the presence of EDs in minorities is likely underestimated for a host of reasons, including the lack of recognition by health care providers and poor access to health care services (Franko et al., 2004).

In the United States, studies of EDs in Asian populations have increased over the past two decades, with diverse findings in terms of ED prevalence (Cummings, Simmons, & Zane, 2005). Some studies have indicated that there is no difference in the prevalence of disordered eating among Asian populations compared to other ethnic groups (Gross & Rosen, 1988; Cachelin, Veisel, Barzegarnazari, & Striegel-Moore, 2000; Le Grange, Stone, & Brownell, 1998). Other studies have provided preliminary evidence that there are higher rates of certain ED symptoms, such as body dissatisfaction, in Asian-American

populations (Robinson et al., 1996; Story, French, Resnick, & Blum, 1995). Cummings, Simmons, and Zane (2005) concluded that numerous methodological challenges of studies with Asian Americans preclude a valid understanding of the prevalence of EDs in this population.

Researchers have also investigated the prevalence of EDs in Latino populations. Gentile, Raghavan, Rajah, & Gates (2007) examined EDs in ethnically diverse, low-income, urban college students. They found that 10% of their sample received an ED diagnosis and the majority of these students were Latino(a). Another study in northern California found that Hispanic girls were more likely to experience body dissatisfaction than their Caucasian peers in a group of the lowest weight girls (Robinson et al., 1996). Unfortunately, EDs often go unrecognized in ethnic minorities or are only acknowledged once they have progressed to a more severe stage (Cummings, Simmons, & Zane, 2005). The importance of increasing our understanding of the prevalence of EDs in various populations is underscored by the growing literature showing that members of ethnic minority groups with EDs are significantly less likely to access or receive treatment (Striegel-Moore & Smolak, 2002).

The prevalence of EDs amongst people in midlife is also a growing area of concern. In the past ten years, psychologists nationwide have reported a startling rise in the number of midlife women seeking treatment for eating problems (Bulik & Taylor, 2005). In their book, *Runaway Eating*, Bulik and Taylor discuss the specific stressors facing women in midlife, such as empty-nest syndrome, and how these stressors lead to problems with eating. Costin (2007) reported that body dissatisfaction in midlife has increased dramatically, more than doubling from 25% in 1972 to 56% in 1997.

EDs in the male population are also receiving growing attention. There has been a gradual increase in the number of men suffering from AN and BN over the past two decades from 1 in 20 cases to possibly 1 in 12 (Maine, 2000). In today's society, men are increasingly being exposed to the muscular-ideal. Researchers at Lucile Packard Children's Hospital and the Stanford University of School of Medicine say that physicians often overlook EDs in boys because they are used to diagnosing girls (Anonymous, 2007). Rebecka Peebles, M.D., an ED specialist, stated, "We're taught to be alert for patients that express a desire to be thin," but "Boys often talk about wanting to be fit and eat healthy, which doesn't set off the same kind of alarm bells" (p. 392). While the number of males suffering from AN and BN is far less than females, 40% of the cases of BED are male (Costin, 2007). Research has also found that there is a higher prevalence of EDs in gay and bisexual men than heterosexual men (Feldman & Meyer, 2007).

Etiological Theories

While an extensive review of the etiology of EDs is beyond the scope of this dissertation, an overview of current theories will be presented. EDs are multidetermined; there is more than one pathway toward the development of an ED, and no one theory is sufficient to explain an ED in a given person.

Biological theory. It has long been understood that EDs tend to run in families. Research has demonstrated that an individual has a higher risk of developing an ED if a relative has one, and an even higher risk if it is a first-degree relative (Costin, 2007). However, it is difficult to separate biological factors (nature) from environmental factors (nurture) because they are always interacting. Twin studies have found that the

concordance rates are substantially greater for monozygotic than for dizygotic twins, indicating a strong etiological role for genetic factors (Strober & Bulik, 2002). While there is evidence that genetics partly explain the occurrence of an ED, this does not mean that all EDs are caused by genetic factors, or that the environment is irrelevant (Costin). Adoption studies would yield the most valid results in separating out genetics and environment but there have been no studies of this kind to date.

Sociocultural theory. Sociocultural influences have a significant role in promoting disturbances of body image and eating. Social pressures from the mass media, peers, and family center around the idealization of thinness and the denigration of people who are perceived as overweight. With respect to media influence, studies have shown that 60% of Miss America contestants and 25% of the models in some magazines are 85% or less than their ideal body weight, meeting one of the diagnostic criteria for AN (Maine, 2000; Stice, 2002). This trend toward excessive thinness correlates with the rise in EDs and suggests that the media contributes to disordered eating. There is also growing support that sociocultural pressures from peers contribute to body image disturbance and disordered eating. Perceived peer interest in dieting and the thin-ideal have been found to correlate positively with eating pathology (Stice).

The influence of family and friends on self-destructive eating behaviors is best explained by social learning theorists, who describe two processes which promote specific attitudes and behavior: social reinforcement and modeling. Through social reinforcement, people internalize attitudes and exhibit behaviors approved of by respected others (Stice, 2002). In the domain of EDs, social reinforcement is delivered by verbalizations or actions of others that support the thin-ideal body image. For example,

an adolescent female may be more likely to pursue a slender physique if she is invited to parties only after she loses weight. She may observe that more rewards accrue to thin people, and she may personally experience more rewards at lower weight. The process of modeling occurs when people observe others, form an idea of how new behaviors are performed, and then use this coded information as a guide for action (Bandura, 1977). For instance, an adolescent male may be more likely to engage in excessive exercise if he sees his peers engage in this behavior. Socialization agents may also model excessive dieting and unhealthy weight-control behaviors, such as the use of laxatives or purging. In the environment of a college dorm there are many opportunities for both modeling and social reinforcement.

Cognitive-behavioral theory. According to cognitive-behavioral theory, the core disturbance amongst ED patients is a characteristic set of thoughts associated with the desire to control eating and weight. A fundamental premise is that self-worth is represented in the size and shape of the body (Vitousek, 2002). Rather than evaluating self-worth on the basis of performance in a multitude of domains, such as work, artistic ability, and interpersonal relationships, people with AN or BN evaluate themselves primarily in terms of their eating, shape, and weight (Fairburn, 2002). Perfectionism, which tends to precede the development of an ED, is another characteristic cognitive disturbances seen in patients with EDs.

In cognitive-behavioral theory, ED patients engage in cognitive distortions, such as overgeneralizing, assuming, magnifying or minimizing, personalizing, magical thinking, or all-or-nothing thinking. A distorted body image, paranoia about all food being fattening, and bingeing based on the belief that eating one *bad* food destroyed a

perfect day of dieting are common cognitive distortions among people with EDs (Costin, 2007). These distortions serve functions, such as providing a sense of safety and control. For example, if people do not trust themselves to make decisions, all-or-nothing thinking provides a strict system of rules for them to follow.

Cognitions of low self-esteem are at the root of EDs, although the mechanisms differ for AN and BN. Fairburn, Marcus, and Wilson (1993) described the following causal sequence for BN: (a) low self-esteem, (b) extreme concerns about shape and weight, (c) strict dieting, (d) binge eating, and (e) purging or self-induced vomiting. Purging helps patients maintain binge eating by reducing their anxiety about weight gain and disrupting learned satiety that regulates food intake (Wilson, Fairburn, & Agras, 1997). Cognitive-behavioral theory of AN explains that patients with this disorder engage in stereotypical eating and elimination behaviors in order to increase their self-worth (Vitousek, 2002). These behaviors are then maintained by the improvement in self-esteem that AN patients report after they have lost weight (Garner, Vitousek, & Pike, 1997).

Psychodynamic theory. Psychodynamic theories on the etiology of EDs emphasize internal conflicts, early relationships, and unconscious forces. There are many psychodynamic theories, such as object-relations and self-psychology, and describing each of them is beyond the scope of this overview. In one psychodynamic theory, symptoms are seen as expressions of a struggling inner self that uses disordered eating and weight control behaviors as a way of communicating underlying issues (Costin, 2007). The symptoms of an ED can be symbolic expressions of psychic aims and defenses (drive-conflict model), symbolic expressions of distorted self and object

representations (object relations model), or nonsymbolic measures used to stem the tide of disrupted self-states threatened with the loss of cohesion of the self (self-psychological model; Goodsitt, 1997).

In their research on BN, Reich and Cierpka (1998) found disturbances in the emotional dialogue between BN patients and their parents. They speculate that the patient's conflicting identifications with the parents result in a consistent pattern of conflict between contradictory parts of the self. The authors also described that many BN patients experience a lack of respect for their boundaries, such as a tactless intrusion into their privacy. Finally, they found that BN patients frequently used defenses involving reversal of affects and they experienced contradictory superego demands. Gabbard (2005) noted that AN patients are characterized by both greater ego strength and greater superego control than BN patients, who may have an inability to delay impulse discharge because of a weakened ego and a lax superego.

With respect to patients with AN, Bromberg (2001) suggested that they transform desire into renunciation through the mechanism of dissociation. The person with AN dissociates into separate self states as a way to wall off traumatic experiences and to promote maximal functioning uncontaminated by intense affects. The patient lacks the form of human relatedness that is needed for her to develop self-regulation of affect states, and therefore, cannot contain desire long enough to make reasonable choices. Parents of AN patients may have been incapable of validating the separate sense of self of their children, and instead may have used them to meet their own needs for soothing and validation. As a result, the patient cannot rely on others to meet her needs and may engage in starvation as a desperate attempt to gain attention.

Early attachment disruption or disturbance has also been described as leading to an ED later in life. Attachment theory describes the process of bonding between caregiver and infant, and the consequences to the infant of the disruption of that bond. Bowlby (1977) described attachment theory as a means of “conceptualizing the propensity of human beings to make strong affectional bonds to particular others, and of explaining the emotional distress and personality disturbance, including anxiety, anger, depression and emotional detachment, to which unwilling separation and loss give rise” (p. 127). Pearlman (2005) described that when an infant is chronically unable to find an attuned emotional connection to her mother, she may attempt to comfort herself from anxiety through thumb or pacifier sucking or demands for food. Pearlman explained that these self-regulatory mechanisms can become imprinted as the primary means of self-care, replacing human attachment, and that this process can lead to the development of an ED. Early attachment disruptions can also explain why EDs are often triggered by experiences of separation and loss, such as puberty, moving away to college, or ending a romantic relationship.

Family systems theory. Specific family factors have been identified in the research on the etiology of EDs. Studies have indicated a higher prevalence of psychopathology in the families of ED patients (Killian, 1994). In particular, family members of patients with AN and BN tend to suffer from affective disorder more than controls (Killian). Research has also found a greater incidence of depression and alcoholism in first- and second-degree relatives of people with BN (Bulik, 1987).

Specific family relations have also been noted in the literature. Minuchin, Rosman, and Baker (1978) reported that the families of patients with AN meet four

characteristics frequently demonstrated by psychosomatic families: enmeshment, rigidity, lack of conflict resolution, and overprotectiveness. The authors described a pattern of enmeshment in the families of patients with AN in which there is a general absence of generational or personal boundaries. Each family member is overinvolved in the life of every other family member to the extent that no one feels a separate sense of identity. Similarly, the parents of children who grow up to suffer from BN often relate to their children as extensions of themselves (Gabbard, 2005). These children are used to validate the self of the parent, and each member of the family depends on all the other members to maintain a sense of cohesion (Gabbard).

Research has also discovered the presence of blurred intergenerational boundaries, adaptability, and conflict in ED families (Killian, 1994). Kog and Vandereycken (1989) found that ED families demonstrated less openness in discussing disagreements between parents and children than controls. The presence of parent-child coalitions in ED families has also been noted in the literature. Clinicians have reported that patients with EDs are *parentified* and perceive triangles in their families (Killian). Supporting the concept that BN families include triangulated relationships, Pole, Waller, Stewart, and Parkin-Feigenbaum (1988) reported that low maternal care scores and high paternal protectiveness scores were the best predictors of BN symptoms. Finally, parental pressure to lose weight and family criticism regarding weight are positively correlated with adolescent eating disturbances (Stice, 2002).

Treatment Options

The number of treatment options available for patients with EDs has expanded greatly in the past two decades. This section will provide a brief overview of the major treatment approaches.

Multidisciplinary treatment. Because of the complex nature of EDs, a multidisciplinary approach to treatment is highly recommended (Kaplan, 2002). First, the treatment team should include a psychotherapist who has experience working with patients with EDs and is trained in treatments that are known to be effective with this population. Second, a psychiatrist who has experience with the medical management of patients with EDs should be involved. Third, nutritionists play a key role in the multidisciplinary treatment of patients with EDs. Treatment providers also need to consider what level of care is appropriate for each patient. Treatment can range from intensive inpatient programs to residential and partial hospitalization programs to varying levels of outpatient care (APA, 2006).

Nutritional rehabilitation. In the treatment of patients with AN, nutritional rehabilitation is of utmost importance. For patients who are markedly underweight and for children and adolescents whose weight has deviated below their normative growth curves, hospital-based programs for nutritional rehabilitation need to be considered (APA, 2006). At the same time, clinicians are in agreement that treatment goals for patients with AN must not be focused narrowly on weight gain (Gabbard, 2005).

Cognitive-behavioral therapy. With respect to BN, cognitive-behavioral therapy (CBT) is the leading evidence-based treatment and is considered the gold-standard among many experts in the field (APA, 2006; Costin, 2007). In 1993, Fairburn,

Marcus, and Wilson published the leading CBT treatment manual for BN patients. This program consists of 19 sessions of individual therapy over the course of 20 weeks. The treatment is problem-oriented and primarily based on the present and future. The first stage of treatment involves psychoeducation and helping the patient to start regaining control over eating. This stage includes learning self-monitoring techniques, self-control strategies, and conducting weekly weighing. The second phase involves an emphasis on regular eating, specifically 3 meals and 2 snacks per day, and addressing the overevaluation of shape and weight. At this point in treatment, cognitive distortions are challenged and the patient begins to learn problem solving techniques. The final phase involves setting realistic expectations and developing a plan for how to deal with setbacks. CBT is also used in the treatment of AN, although the empirical validation is not as strong as for BN and there is a need for further research in this area.

Psychodynamic therapy. The value of psychodynamic treatments for EDs has also been clearly described and may be recommended on clinical grounds when short-term treatments are ineffective (Garner & Needleman, 1997). The common feature of all psychodynamic theories of EDs is the belief that if the underlying causes of disordered behaviors are not addressed, they may subside for a time but will often return (Costin, 2007). Gabbard (2005) described that psychodynamic therapy with AN patients often takes several years of painstaking work because of the formidable resistance posed by the patient. During this process it is important to avoid excessive investment in trying to change the eating behavior, avoid interpretations early in therapy, and carefully monitor countertransference.

Pearlman (2005) wrote about ED treatment considerations from an attachment theory perspective. She described that many professionals and parents focus narrowly on the symptoms of purging or weight gain or loss, and thereby reinforce the patient's substitution of symptom for relatedness. Pearlman described that it is important for professionals, and if possible parents, to be patient and to not attempt to control the patient's feelings or symptoms as a way of containing their own anxiety. She described that this approach can contribute tremendously to the success of treatment by not re-creating a misattuned pattern of caretaking.

Interpersonal psychotherapy (IPT), a modified form of psychodynamic therapy, is another treatment used for patients with EDs. IPT is designed to help people identify and address current interpersonal problems. A novel aspect of IPT for BN is the evaluation of possible interpersonal triggers of individual episodes of binge eating, as binges are commonly precipitated by interpersonal events (Fairburn, 2002).

Family therapy. In the field of EDs, there is an acceptance of a problem in the functioning of the families of these patients, and hence an acknowledgment of a possible place for family interventions (Dare & Eisler, 1997). Family therapy is the treatment of choice for AN patients who are 18 years old or younger and live at home (Garner & Needleman, 1997). In family therapy for AN, there is a strong focus on helping parents manage their child's symptomatic behavior. The therapist helps the parents overcome their sense of helplessness and leads them to find a way of mobilizing the family's resources (Dare & Eisler, 2002). As treatment progresses and the patient gains weight, therapy involves a discussion of wider family issues along with an exploration of the

patient's feelings and beliefs about her problems, body image, and self-esteem (Dare & Eisler, 2002).

Integrative treatment. Many practitioners in the field of EDs choose to use an integrated approach to treatment. In general, there is movement in the field of psychotherapy toward eclecticism and integration of different therapeutic approaches (Garfield, 1994). The wisdom of integrating psychotherapeutic interventions is increasingly evident with the demonstrated effectiveness of different forms of treatment (Garner & Needleman, 1997). The American Psychiatric Association's *Practice Guidelines for the Treatment of Patients with Eating Disorders, Third Edition* (2006), states that using psychodynamic interventions in conjunction with CBT and other psychotherapies may yield better global outcomes than CBT alone in the treatment of patients with BN.

Treatment Outcome

The course and outcome of EDs are highly variable. Some individuals fully recover and others experience a chronically deteriorating course of the illness over their lifetime. Aggregate results from long-term follow-up studies of AN patients indicate that nearly 50% eventually make a full recovery, 20%-30% show residual symptoms, 10-20% remain severely ill, and 5-10% die of related causes (Steinhausen, 2002). For patients with BN, estimates of remission over time range from 31% to 74%; however, remission is often fleeting, and relapse is common (Wilson, Grilo, & Vitousek, 2007). Mortality rates in EDs, AN in particular, are among the highest in psychiatric illnesses (APA, 2006). Of individuals who are admitted to university hospitals, the long-term mortality rate for AN is 10% (APA, 2000).

Purpose and Importance of this Project

Patients with EDs have long been described as difficult for clinicians to treat (Kaplan & Garfinkel, 1999). A greater understanding of the factors that contribute to this difficulty could help improve treatment outcome. Studies from many ED centers suggest that the dropout rate for treatment is significant, suggesting that patients are often dissatisfied with the various treatments they receive (Yager, Landsverk, & Edelstein, 1989). Moreover, in the treatment of AN, therapists often describe resistance as a common experience among patients, professionals, and relatives (Paulson-Karlsson, Nevenon, & Engström, 2006). In order to better understand the patient's motivation to engage actively in treatment, as well as the treatment factors that contribute to success, it is important to attend to patients' perspectives on treatment.

Patient satisfaction plays a central role in the therapeutic alliance and treatment outcome. When patient values are integrated with the best research evidence and clinical expertise, clinicians and patients will create a therapeutic alliance that optimizes treatment and quality of life (Sackett, Straus, Scott, Rosenberg, & Haynes, 2000). When treatment and recovery from an ED are defined only by clinicians and researchers, important aspects may be overlooked. Given the high potential for death and chronicity, the patient's perspective of the process of recovery is vital for improved self-care and clinical intervention (Weaver, Wuest, & Ciliska, 2005).

Recently, the number of studies on patients' experiences in ED treatment has significantly increased. Qualitative and quantitative studies have been conducted on a variety of topics including the therapeutic relationship, helpful components of treatments, and patients' recommendations for areas of improvement. Despite the need for further

research in this area, the literature to date provides fruitful information for practitioners working with patients suffering from EDs.

The purpose of this project is to create a resource booklet that synthesizes the findings from research on patients' perspectives on treatment. This booklet will be designed for psychotherapists in outpatient settings with an interest or specialty in working with patients with EDs. It may also be utilized by psychotherapy students who have an interest in working in this field. Patients' perspectives on what is helpful and not helpful in treatment will be highlighted, along with recommendations and resources for practitioners working in this field.

Chapter II: Literature Review

Introduction

Since the 1980s, patients' perspectives on treatment of EDs have received growing attention in order to better understand what is helpful and not helpful in ED treatment (De la Rie, Noordenbos, Donker, & van Furth, 2006). Previously, there was a reluctance to seek patients' views because of the belief that those with mental illness were unable to give valid feedback about their treatment (Clinton, Björck, Sohlberg, & Norring, 2004). Recently, however, qualitative and quantitative studies on patients' perspectives on ED treatment have been conducted in numerous countries with people of all ages and all diagnoses, including AN, BN, ED-NOS, and BED. Researchers have sought feedback from recovered individuals and patients in recovery from both inpatient and outpatient treatment settings.

For this literature review a comprehensive search of the studies on patients' perspectives on ED treatment was conducted. Details about each of the major studies in this field are provided in Appendix A. The next step of this review involved a critical analysis of these studies, followed by a content analysis in order to create categories for the factors identified by patients in the research studies on patients' perspectives. From this analysis, the author then created a list of ten treatment elements: the therapeutic relationship, provision of social support, collaborative treatment, focus on emotions, focus on underlying issues, inclusion of psychoeducation, therapist's knowledge of EDs, behavioral interventions, appropriate use of medication, and therapist's competence in family dynamics. A complete explanation of the methodology utilized in this literature review is described in Chapter III.

This chapter begins with studies on overall treatment satisfaction from the patient's perspective, followed by research on different treatment modalities. Then, the ten treatment elements are critically reviewed. Finally, this chapter presents information on studies that compared patients' perspectives to therapists' perspectives.

Treatment Satisfaction

Studies on overall treatment satisfaction from the patient's perspective have yielded varied results. In the United States, Maine (1985) completed one of the first studies on patients' perspectives on ED treatment. Maine conducted in-depth interviews with 25 people who recovered from AN. She found that 5 participants felt that their treatment was essential to recovery, 3 saw their treatment as harmful to their recovery, and 16 rated their treatment as equivocal, expressing that they would have recovered without treatment. Also in the United States, Yager et al. (1989) analyzed questionnaires from 641 women with EDs who responded to an article in *Glamour Magazine*. In this study, respondents generally felt that professional treatment only helped *a little*. This particular sample of women is not likely to be representative of all women with EDs, and the respondents may have had varied treatments from providers of unknown competence. Also, those studies were from the 80s, and professional knowledge about EDs has increased since then.

Of greater interest are studies of patients who have completed specific treatment programs. These studies show greater satisfaction, while at the same time demonstrating need for improvement. In the United Kingdom, Button and Warren (2001) completed a study with 36 participants who received treatment for AN. The participants were followed up 7.5 years after receiving treatment at a specialized ED service for adults. The

researchers utilized a semi-structured interview and a questionnaire. They found that 33.3% of their participants felt that treatment was helpful, 33.3% felt that treatment was mixed helpful and unhelpful, and 19.5% felt that treatment was unhelpful.

In New Zealand, Swain-Campbell, Surgenor, and Snell (2001) completed a study with 120 ED patients three months after their first contact with The Christchurch Eating Disorder Service. This service includes the sole specialist, hospital-based inpatient treatment center within the New Zealand Public Health System. In this study, 75% of respondents rated assessment and treatment as either good or excellent. Overall, there was an 85% approval rating for the various aspects of service provision that were measured by the forced-choice portion of their questionnaire.

A better methodology for studying satisfaction includes pretreatment measures, in order to analyze which patients are least satisfied. In Sweden, Clinton et al. (2004) completed a multicenter study with 469 ED patients. The patients were followed up 36 months after initial assessment and a questionnaire was utilized. It was found that 38% of patients were *highly satisfied* with treatment, while 39% were *satisfied* and 23% were *unsatisfied*. The researchers also discovered that unsatisfied patients were less prepared to change their eating habits, had more difficulties with weight acceptance, had higher levels of conflict with their fathers, and expected less from treatments focusing on control of eating problems. They concluded that the field may be effective in satisfying patients who are predisposed to therapy that focuses on support and control of eating problems, but has more difficulty with patients who have more significant interpersonal problems and who are not as focused on their ED symptoms. In another Swedish study, Paulson-Karlsson et al. (2006) analyzed questionnaires from 34 AN patients who received family

treatment at Queen Silvia Children's Hospital. It was found that 73% of the patients felt that their pretreatment expectations had been fulfilled. In addition, 10 patients in this study who did not initially want any help felt that they had been helped in the end.

Many researchers have discovered negative effects of ED treatment. Bell (2003) conducted a review of twenty studies that utilized qualitative research or surveys with people who have experienced an ED. She concluded that treatment can be not only ineffective but experienced as negative. Patients report negative experiences when they do not have control over the treatment process, such as with treatments that focus exclusively on weight. In the Netherlands, Noordenbos, Jacobs, and Hertzberger (1998) analyzed letters written by chronic ED patients to the Dutch Foundation of Anorexia and Bulimia Nervosa. They found that ED patients were often afraid of treatment because of negative treatment experiences. In Button and Warren's (2001) study of 36 participants who received treatment for AN in the United Kingdom, one participant stated the following about treatment: "I think it was pretty horrible really...staying in your pajamas till you get to your maintenance weight. You just lose your self-worth...mentally it's so demoralizing...living, sleeping, eating in one room...it was all about gaining weight" (p. 84). Another participant in this study expressed, "I felt belittled...The staff were old-fashioned, you were not treated as a person, but as someone with anorexia nervosa" (p. 85). In Canada, Weaver et al. (2005) completed a qualitative study with 12 women who recovered or were recovering from AN. They found that the majority of participants perceived treatment as traumatic and defined recovering from AN to some extent as their ability to survive treatment.

In summary, research conducted over the past two decades on treatment satisfaction from the patient's perspective has yielded mixed results, with many patients reporting that treatment for EDs is unhelpful or traumatic. Therefore, there is a great need to improve treatment satisfaction by examining more carefully the facets of treatment that patients find helpful and not helpful.

Treatment Modalities

Numerous studies have examined patients' satisfaction with different types of treatment modalities (i.e., individual, family, and group therapy). Several of these studies have noted that individual therapy is seen as widely helpful to patients recovering from EDs. In the United States, Beresin, Gordon, and Herzog (1989) conducted semi-structured interviews with 13 women who recovered from AN. The participants were recruited from an ad placed in a newsletter of an organization devoted to helping ED patients. The researchers found that individual psychotherapy was by far the highest rated of all treatments. One participant speaking of individual therapy expressed, "I feel as though I was raised again from infancy, building a sense of myself" (p. 114). This study included a small group of women and is not likely to be representative of all sufferers of AN. Also in the United States, Lemberg and May (1991) conducted a study with 28 patients who received treatment for AN or BN at an inpatient facility. The participants' length of stay in treatment ranged from one to six weeks and they completed a *Patient Opinion Survey* at the time of discharge. One of the most helpful components of treatment reported in this study was one-to-one sessions with psychiatrists and psychologists.

In the United Kingdom, Button and Warren (2001) found from their study of 36 participants who received treatment for AN that 91% of the participants felt that individual psychotherapy or counseling was helpful. In Sweden, Paulson-Karlsson et al. (2006) found from their quantitative study of 34 patients who received treatment for AN that 79% of patients felt that individual therapy was of great help and 14% felt that it was of some help. The results of these studies on individual psychotherapy are not representative of people with BN as only one of the studies in this area included BN participants.

Multiple studies have investigated patients' satisfaction with family therapy. Paulson-Karlsson et al. (2006), in their study of adolescents who received treatment for AN, found that 12% of participants felt that family therapy was of great help, 53% felt that it was of some help, and 35% felt that it was of no help. Krautter and Lock (2004) investigated consumers' satisfaction with a manualized family-based treatment for adolescent AN utilized at the Stanford School of Medicine. The treatment was a version of the Maudsley approach to family therapy and included three phases which spanned six to twelve months. The first phase consisted of focusing on correcting severe malnutrition by having the parents take charge of feeding their child. The second phase encouraged parents to teach their child to take more control over eating herself. The third phase focused on the impact AN has had upon developing a healthy adolescent identity. In this study, adolescent patients as a whole felt that all treatment components were effective. However, a quarter of the participants in the study, which included parents, felt that individual therapy, more family therapy, and focusing on other issues besides AN would be more helpful. The results of these two studies are not representative of all female AN

patients' perspectives on family therapy because the methods of treatment at the specific treatment facilities studied are not the only approaches to family therapy.

Other studies have included participants with varied family therapy experiences. Beresin et al. (1989), in their qualitative study of 13 women who recovered from AN, also found that family therapy received mixed reviews. One dissatisfied participant expressed:

Our therapist was totally inducted in the sick system. The problem was never redefined. In two years she never got my parents to deal with their issues and the kids to deal with theirs. Bad family therapy made individual therapy twice as hard. The therapist never disempowered my parents with regard to food, and she never took the focus off me, explained about my being a symptom bearer, even if it made my parents angry. She was sucked into my mother's control and little work was done. (p. 117)

Conversely, family therapy was seen as invaluable by other participants. One participant expressed:

This therapy enabled the family to bring out conflicts in a safe setting. What was most helpful was to learn that everyone and no one was to blame and to learn that in spite of our anger, mistakes, and hurt, we loved one another very deeply, and to discover that anger, mistakes, and hurt can coexist with love. (p. 118)

Rosenvinge and Klusmeier (2000) completed a study with 321 present and former ED patients. The researchers mailed questionnaires to members of an ED organization and inquired about treatment satisfaction. They found that participants were highly satisfied with outpatient individual and group psychotherapy, and to a less extent with

family therapy. In Bell's (2003) literature review of qualitative studies and surveys on patients' perspectives it was concluded that individual and group therapy are consistently reported as helpful and that early studies report negative views of family therapy. In summary, client satisfaction studies have found that individual psychotherapy is seen as widely helpful. The fact that the utilization of family therapy has received mixed reviews from ED patients may be related to the wide range of competence among therapists.

Ten Treatment Elements

Researchers of patients' perspectives on ED treatment have sought feedback on a variety of treatment components. The author of this project completed a critical review and content analysis of the treatment areas that researchers have investigated. A list of ten treatment elements was created from this analysis: the therapeutic relationship, provision of social support, collaborative treatment, focus on emotions, focus on underlying issues, inclusion of psychoeducation, therapist's knowledge of EDs, behavioral interventions, appropriate use of medication, and therapist's competence in family dynamics. This section includes a review of each of these treatment elements.

The therapeutic relationship. The vast majority of studies on patients' perspectives on EDs have emphasized the importance of a strong therapeutic relationship and humanistic factors in treatment. Rorty, Yager, and Rossotto (1993) interviewed 40 women in the United States who were recovered from BN for a minimum of one year. The participants were recruited via newspaper advertisements and referrals from local care providers. The researchers in this study concluded: "It is clear that empathy, understanding, and respect for the bulimic woman as a whole person, and not merely as a symptom constellation, are desirable, healing qualities of a care provider" (p. 259).

In South Africa, Le Grange and Gelman (1998) completed a qualitative study with 21 females who received treatment at an outpatient university-based ED service. The participants were interviewed on average one year after they received either family counseling or CBT. More than half of the participants in this study expressed that they were helped by the *supportive and understanding* environment provided by treatment. One participant expressed that it was helpful to experience, “a climate in which I could be totally honest about my symptoms...about all the gory details” (¶ 13).

In Norway, Rosenvinge and Klusmeier (2000) found from their quantitative study of 321 members of a Norwegian organization for ED patients that *understanding* was the most frequently identified helpful therapist quality and it was rated far more important than *knowledge of EDs*. In another Norwegian study, Pettersen and Rosenvinge (2002) completed a study with 48 women who received professional treatment for an ED. The participants were recruited from patient organizations and a university ED unit. The researchers utilized a qualitative, open interview and several questionnaires. In this study, it was found that treatment satisfaction was strongly associated with experiencing a therapeutic relationship which emphasized support, empathy, respect, understanding, and seeing the individual beyond the symptoms. A typical statement of a participant in this study was, “I got the feeling that the therapist really cared about me, I trusted her and I didn’t need to cover up” (p. 66).

In the United Kingdom, Button and Warren (2001) completed a mixed-methods study with 36 participants who received treatment for AN. They found considerable consensus amongst the participants regarding the importance of having a good relationship with a therapist. One participant in this study stated, “You need to see

someone professional on a one-to-one. You've got to have trust and build a relationship and get on with them" (p. 87).

In the Netherlands, De la Rie et al. (2006) completed a questionnaire study with a large community-based sample. The researchers found that helpful components of therapy were a good working alliance and feeling understood and supported. One patient expressed, "It is nice when someone really listens to you and tries to understand you instead of judging you" (p. 672). De la Rie, Noordenbos, Donker, & van Furth (2008) completed another study in the Netherlands with 156 current ED and 148 former ED patients. The researchers again recruited participants from the community and utilized a questionnaire. They found that 5 of the 10 most important criteria of quality treatment by ED patients involved the therapeutic relationship: 1 trust in therapist, 2 being taken seriously, 3 treatment that addressed the person, 6 being respected, and 10 being accepted as you are.

In Canada, Federici and Kaplan (2008) completed a study with 15 patients with AN who had successfully completed intensive treatment at Toronto General Hospital. The treatment primarily focused on nutritional rehabilitation and group-based cognitive and behavioral interventions. The researchers found that the degree to which participants felt a sense of safety, support and acceptance in the therapeutic relationship was reported to have either helped or hindered recovery. It was concluded that, "placing a greater emphasis on the development of the therapeutic alliance over the course of intensive treatment and throughout the relapse prevention phase may improve treatment outcome" (p. 8).

In her pioneering book, *The Golden Cage: The Enigma of Anorexia Nervosa*, Bruch (1978) described that many AN patients complain that they found it difficult to talk with their therapist, that there had been long silences, or that the therapist focused on topics they felt did not matter. In Bell's (2003) review of qualitative studies and surveys on consumers' perspectives, she concluded that supportive and empathic relationships are critical to recovery from an ED. Clearly, patients who have experienced an ED have voiced the unique importance of having a positive relationship with a therapist. The studies on patients' perspectives on the therapeutic relationship have included a wide range of ED diagnoses and both qualitative and quantitative methodologies. However, there are limitations to the generalizability of these findings to patients in the United States as only one study was conducted in this country.

De la Rie et al. (2008), in their study of a large community based sample in the Netherlands, explain that patients with EDs may stress the importance of a good therapeutic alliance because they find it particularly challenging to engage in a relationship with a therapist. The authors further explain that this difficulty may be due to early life experiences when mental representations about oneself in relationship with others are formed. Pearlman (2005), in her article on EDs from an attachment theory perspective, described that ED patients have an intense fear of forming attachments, including therapeutic attachments. She explained that ED patients cling to their symptoms "to protect them from falling into unending realms of terror and annihilation, realms which stem from early infant trauma" (p. 230). Pearlman described that many ED patients unconsciously resist relating to the therapist. It is probable that ED patients

underscore the importance of the therapeutic relationship in treatment because they have a great need to feel safe, and connected to another being.

Provision of social support. Individuals with a history of an ED have emphasized the importance of having supportive relationships while in recovery. Rorty et al. (1993), in their qualitative study of 40 women who recovered from BN, discovered that while patients reported that support from friends, family, or a romantic partner was very helpful in treatment, parents were generally viewed as unhelpful. A substantial number of mothers (55%) and fathers (33%) were perceived as being actively harmful to the women's recovery process (e.g., deliberately buying tempting food, blaming the woman for having the disorder, or discouraging or undermining the women's efforts to get help). Pettersen and Rosenvinge (2002), in their mixed-methods study of 48 women, found that patients frequently described that people important to them were often "the first to know about their problems, the first to encourage them to seek professional help, and the main source of trust, acceptance, and practical and emotional support" (p. 67). Similarly to the participants in Rorty and colleagues' study, the participants in this study valued a distance from parents as helpful in recovery. Tozzi, Sullivan, Fear, McKenzie, and Bulik (2003) conducted a study with 70 women who were referred to an ED service for AN. The researchers conducted extensive interviews including open-ended questions about the patients' beliefs concerning the causes of AN and factors that led to recovery. They found that the most commonly mentioned recovery factor among AN patients was having a supportive relationship or partner. In Bell's (2003) review of studies on consumer satisfaction in ED treatment, it was concluded that experiences outside treatment, particularly supportive relationships, significantly impact recovery and

therefore education and support to families and carers should be provided in all specialist services.

Several studies have also identified the importance of receiving support from other ED patients. Rorty et al. (1993), in their qualitative study of 40 women who recovered from BN, found that contact with other BN sufferers was the second most helpful treatment-related experience after receiving empathy and understanding. Pettersen and Rosenvinge (2002), in their mixed-methods study of 48 women, discovered that meeting with other sufferers promoted a feeling of being able to recognize oneself in others, helped patients realize their own potentials, and provided hope with respect to their recovery. De la Rie et al. (2006), in their questionnaire study of a large community-based sample, also found that support from other ED patients was mentioned as valuable in the recovery process. Finally, Federici and Kaplan (2008), in their qualitative study of 15 women who weight-recovered from AN, found that women who maintained a healthy weight stated that they felt safe, supported and validated by fellow group members throughout treatment. One patient expressed, “I was with fellow women that suffered with the same thing so that allowed me to be open about issues... and because people were speaking about them, I was able to speak about them” (p. 5).

In review, patients with EDs have noted in numerous studies that supportive relationships, including relationships with other sufferers, are a key component to successful treatment. The studies on this topic have included both AN and BN participants and qualitative and quantitative methodologies. There is a great need for studies on social support to include male participants as none of the five studies in this area included males.

Collaborative treatment. Multiple studies have highlighted the importance of establishing a collaborative treatment approach wherein the patient has some control over the process. In 2001, Button and Warren found from their mixed-methods study of 36 women who received treatment for AN that a common theme was the patients' perspective that their ED had been a response to a sense of loss of control in one or more areas of their lives. The authors recommend that treatments for patients with EDs take into account the patient's high level of need for control. In 2004, Clinton et al. concluded from their quantitative study of 469 ED patients that patients want therapists to listen more carefully to them and consider their expectations when planning and providing treatment. In 2006, Paulson-Karlsson et al. found from their quantitative study of 34 patients who received treatment for AN that a positive experience of treatment involved the patient's participation in treatment planning and agreement on the content of treatment. Also in 2006, De la Rie et al. concluded from their qualitative study of a large community-based sample that it is important to negotiate treatment goals with ED patients at different moments during the process of change, and that the extent to which this occurs may explain differences in satisfaction with treatment.

In her review of consumer studies on ED treatment, Bell (2003) concluded that patients value having some control over the process and pace of treatment. The author explained the importance of training professionals who work with ED patients so that they can learn how to develop and maintain a collaborative working relationship with patients. In conclusion, individuals with EDs have identified the importance of treatment providers seeking and incorporating their input throughout the treatment process. However, it is important to note that only two of the studies in this area included male

participants: one study included 6 males and the other study included 7 males. There is also a need for more qualitative studies on collaborative treatment approaches as only one study included an interview. Finally, while the studies in this area were conducted in multiple countries, none of these studies included information about the ethnicity of the participants; therefore, it is difficult to ascertain the applicability of these findings.

Focus on emotions. A few studies have investigated patients' perspectives on the importance of addressing emotions in treatment. Beresin et al. (1989), in their qualitative study of 13 women who recovered from AN, found that patients felt that therapy helped them discover feelings, learn why they felt guilty, and realize that anger cannot destroy the person it is aimed at. The researchers found that the toleration of feelings, particularly anger, by both the patient and therapist, was extraordinarily important in treatment. Le Grange and Gelman (1998), in their qualitative study of 21 females at a single specialty service site, found that when patients were dissatisfied with treatment they reported that their personal problems and feelings were not dealt with sufficiently. One patient specifically stated that treatment neglected to deal with the *emotional side* of the ED. Federici and Kaplan (2008) interviewed women who weight-recovered from AN after intensive treatment at a Canadian hospital. The interviews were conducted, on average, 14 months after treatment and two groups emerged: those who maintained a healthy weight and those who relapsed. The participants who relapsed felt that the identification and processing of core emotional issues were overlooked in their treatment. These participants felt that they were left vulnerable and unskilled in managing ongoing emotional stressors. On the other hand, participants who maintained a healthy weight

attributed their success to having dealt with negative feelings and being prepared to cope with such feelings in the future. One participant expressed this view:

I am able to tolerate negative emotions and that has had a very positive influence [on] stay(ing) well...on my getting recovered and maintaining it. So, the negative emotions...[I'm] totally able to feel them and not get overwhelmed by them and not have them translate into negative behaviors...that's fundamentally important!
(p. 6)

In summary, ED patients have noted through several studies the importance of therapists helping them identify, process, and manage emotions. However, it is important to note that all three of the studies in this area had small sample sizes (13-21) and only one study included BN participants. Therefore, additional research including larger sample sizes and a wider range of ED populations is needed in this area. In addition, there is a great need for studies on emotions to include participants with ranging ethnic backgrounds as all three of the studies in this area included solely Caucasian participants. Moreover, none of the studies that addressed emotions included male participants.

Focus on underlying issues. Several studies have found that patients find it helpful to address the issues underlying an ED, rather than just eating behaviors and weight. Rorty et al. (1993), in their study of 40 women who recovered from BN, found that patients expressed that one of the most helpful aspects of treatment was work on underlying issues, and they concluded that addressing underlying issues is crucial in recovery. Pettersen and Rosenvinge (2002), in their mixed-methods study of 48 women who suffered from an ED, found that highly valued components of treatment for patients were a better understanding of their situation and help to deal with issues underlying the

ED. A typical statement by a patient was, “The therapist asked questions that opened my mind and made me capable to change my way of thinking” (p. 66). De la Rie et al. (2006), in their quantitative study of a large community based sample, found that patients viewed gaining insight into one’s problems as a helpful component of treatment.

Vanderlinden, Buis, Pieters, and Probst (2007) completed a European study of patients who received CBT in either an inpatient or outpatient setting. The researchers analyzed questionnaires from 132 patients (56 patients with AN, 65 patients with BN, and 11 patients with BED). The participants reported that gaining insight into their ED and understanding the meaning of the ED in their daily life is very important in treatment.

Federici and Kaplan (2008), in their qualitative study of 15 women who weight-recovered from AN, found that participants who relapsed after treatment felt that issues underlying their ED were not adequately addressed in treatment or in follow-up care. One patient expressed:

I feel like I didn’t deal with any of the issues that were there to begin with. The bereavement, the self-esteem issues...I hadn’t dealt with why I had this eating disorder. How can I fix something when I don’t even know what the cause of it is? (p. 5)

In summary, many patients with EDs as well as recovered individuals have underscored the significant value of working on underlying issues while in treatment. The studies in this area have included both AN and BN participants and quantitative and qualitative methodologies. However, only one study that addressed the importance of working on underlying issues included males and that study only had three male

participants. Finally, the results of these studies are not representative of people with EDs in the United States as only one of these studies was conducted in this country.

Inclusion of psychoeducation. Three patient perspective studies have identified the benefits of integrating psychoeducation in the treatment of EDs. Rorty et al. (1993), in their study of 40 women who recovered from BN, found that education about EDs was one of the most helpful treatment related experiences. Le Grange and Gelman (1998), in their qualitative study of 21 females, found that one third of the participants who received CBT expressed that receiving information about EDs was helpful. One participant stated, “Therapy gave me an understanding of the vicious binge cycle and understanding [it] enables control” (¶15). Federici and Kaplan (2008), in their qualitative study of 15 women who weight-recovered from AN, found that weight-recovered AN patients stated that specific interventions, such as psychoeducation, were essential components of recovery. The results of these three studies are not applicable to the male population as none of these studies included male participants. In addition, these studies included limited samples in terms of ethnicity, as only one study included Asian, African-American, and Hispanic participants. Finally, the studies on psychoeducation have included limited sample sizes, with a range of 15 to 40.

Therapist’s knowledge of eating disorders. Patients’ perspectives on the importance of a therapist’s knowledge of EDs is another area that has been researched. In the United States, Beresin et al. (1989) concluded from their qualitative study of 13 women who recovered from AN that patients want therapists to have a solid working knowledge of EDs. However, the authors found that patients “warn against inflexible

adherence to one's own theory, a stance that impairs listening and understanding the patient as an individual" (p. 114).

In the United Kingdom, Newton, Robinson, and Hartley (1993) completed a study with 1638 females and males who were members of the Eating Disorders Association. Sixty-three percent of the participants were suffering from an ED and the remainder were recovered. The participants were given the opportunity to suggest possible sources of improvement in services for people with EDs and 60% of the respondents suggested more specialists for EDs.

In the Netherlands, De la Rie et al. (2006) found from their questionnaire study with a large community-based sample that negative aspects of nonspecialized treatment were a lack of understanding or empathy due, in part, to a lack of knowledge of EDs. This study implies that patients feel that without adequate knowledge of EDs, therapists cannot understand the patient's experience. Finally, in Sweden, Paulson-Karlsson et al. (2006) found from their quantitative study of 34 patients who received treatment for AN that a positive experience of treatment included the therapist being knowledgeable and understanding of EDs.

Two studies conducted in Norway have yielded ambiguous results about the importance of a therapist's knowledge of EDs. Rosenvinge and Klusmeier (2000), in their questionnaire study of 321 participants, found that patients who perceived their therapists as experts on EDs were more satisfied with their treatment; however, only 35% of participants rated *knowledge of EDs* as important. When given the opportunity to list recommendations for services for patients with EDs, only 11% of the participants in this study requested more specialists in EDs. Pettersen and Rosenvinge (2002), in their

mixed-methods study of 48 women, found that therapists' specific knowledge about EDs was not judged as a matter of vital importance by women who received treatment.

In conclusion, the literature on the importance of a therapist's knowledge of EDs shows mixed results. Some studies have found that patients want therapists to have a solid working knowledge of EDs and think that there should be more specialists in the ED field. Two other studies found ambiguous results, with some patients reporting that specific knowledge about EDs is not vitally important. The studies on the importance of a therapist's knowledge of EDs have included both female and male participants and both qualitative and quantitative methodologies. On the other hand, only one study provided information about the participants' ethnicities and that study reported that all participants were Caucasian.

Behavioral interventions. Behavioral interventions have a long history in the treatment of EDs. The research on patients' perspectives on behavioral interventions has yielded mixed results. Le Grange and Gelman (1998), in their qualitative study of 21 females who received ED treatment, found that more than half of the participants in their study felt that specific behavioral strategies, such as keeping a diary and practicing the use of distracting behaviors, were helpful. One participant expressed, "Therapy gave me coping strategies. If I had a binge feeling, therapy helped me to do other things instead" (¶ 12). However, half of the participants in this study also reported that some behavioral techniques were unhelpful. Specifically, they experienced negative reactions to the demand to monitor food intake when symptoms were perceived to be too powerful, and they complained about the prescriptive nature of treatment. In addition, Newton et al. (1993), in their questionnaire study of 1638 participants, found that 69% of the patients

who received behavior therapy reported that it was unhelpful or made their situation worse. Federici and Kaplan (2008), in their qualitative study of 15 patients who received treatment for AN, found that participants who relapsed reported feeling dissatisfied with their treatment because behavioral goals (e.g., weight restoration) overshadowed the identification and processing of core psychological issues. Regardless of having gained weight, these women felt that they were not well prepared for life after treatment.

Much of the published literature describes that interventions which focus exclusively on weight are viewed negatively by patients and there is a need to address wider issues than food and weight in treatment (Bell, 2003). Noordenbos et al. (1998) found that patients who received tube feeding or behavior therapy were usually negative about these treatments. During or after receiving these treatments, these patients became depressed and sometimes even suicidal.

In summary, patients with EDs have identified that some behavioral interventions (e.g., diary keeping) are helpful components of therapy, whereas other behavioral interventions (e.g., interventions which focus exclusively on weight) are not helpful and can even be harmful. It is important to note that only one of the studies on patients' perspectives of behavioral interventions included BN participants and that study included a small sample size ($n=21$). In addition, only one of the studies in this area included male participants, with that study being only 2% male. Finally, while the studies in this area were conducted in several different countries, only two studies reported information about the participants' ethnicities, with both reporting that all participants were Caucasian.

Appropriate use of medication. Medications have been widely utilized and advocated for EDs (Garfinkel & Walsh, 1997). Research has found that antidepressants, such as selective serotonin reuptake inhibitors (SSRIs), are effective as one component of treatment for BN and BED patients (APA, 2006). SSRIs in combination with psychotherapy are widely used in treating patients with AN (APA, 2006). Button and Warren (2001), in their study of 36 patients who received treatment for AN, found that 79% of their participants felt that drug therapy was helpful to some degree. Pettersen and Rosenvinge (2002) analyzed questionnaires of individuals who received treatment for AN, BN, or ED-NOS and found that antidepressant medication was seen as beneficial. Medication was experienced as a buffer to strong emotions, a help to overcome a crisis, and a regulator of food and hunger.

In contrast, several studies of patients' perspectives have found that patients' viewed medications as unhelpful (Bell, 2003). Tozzi et al. (2003) found that out of 70 women who were referred for treatment of AN only 4 patients mentioned medication as a recovery factor and none of these individuals claimed that medication affected core AN symptoms, a finding they found consistent with the literature that they had consulted. Newton, Hartley, and Sturmey (1993) conducted a study with 54 participants with EDs who attended a college-based, group counseling service. They asked the participants to evaluate four treatments: counseling, systematic desensitization, goals and relaxation, and drug therapy. The researchers found that drug treatment was rated significantly less favorably than the other three treatments.

Two studies on patients' views of medication in ED treatment discovered mixed reviews. First, in a study of individuals with AN, BN, and EDNOS, Newton et al. (1993)

found that 50% of patients viewed medication as slightly helpful or very helpful and 50% viewed medication as unhelpful or making their situation worse. Second, Beresin et al. (1989) found that none of their participants felt that medication was helpful in alleviating symptoms of AN; however, it was viewed as helpful for anxiety, depression, and insomnia. One participant expressed, “Medication had a normalizing effect and allowed me to deal more effectively with my ED” (p. 118).

In conclusion, patients have reported mixed views toward utilizing medication in the treatment of EDs. The studies on medication are not representative of all women with BN as only two studies included participants with BN, with one of those studies reporting that BN was underrepresented. In addition, while the studies on medication were conducted in several countries, only one of the studies included information about the participants’ ethnicities and that study reported that all participants were Caucasian.

Therapist’s competence in family dynamics. Two studies have uncovered patients’ views of the importance of family dynamics in relation to their ED. First, Tozzi et al. (2003) interviewed 70 women about their beliefs concerning the causes of AN and factors that lead to recovery. They found that the most frequently mentioned causal factor of the ED was a dysfunctional family. The authors of this study report that while there is no evidence of a *typical* AN family, specific patterns of family interaction have been observed (e.g., rigidity, overprotectiveness, excessive control, and marital discord). It has also been reported that patients with BN “view their families as conflicted, badly organized, uncohesive, and lacking in nurturance or caring” (Vandereycken, 2002b, p. 216). On the other hand, Beresin et al. (1989) reported that participants in their study (13 women who recovered from AN) emphatically stated that a serious error in

psychotherapy is to blame parents excessively. One participant stated, “My first therapist hurt me because he refused to speak with my parents or deal with them. He tried to portray my parents as the enemy and painted my mother as a demon. This was extremely harmful” (p. 114). It is important to note that there is a need for studies on BN patients’ perspectives on addressing family dynamics in therapy as neither of the studies on this topic included BN patients. In addition, neither of the studies in this area included male participants. Last, only one of these studies included information on the ethnicity of the participants, with that study reporting that all participants were Caucasian.

Research on the etiology of EDs has also provided information about ED patients’ family relations. In their research on BN, Reich and Cierpka (1998) found disturbances in the emotional dialogue between patients and their parents. They speculate that the patient’s conflicting identifications with the parents result in a consistent pattern of conflict between contradictory parts of the self. They also found that many BN patients experience a lack of respect for boundaries, such as a tactless intrusion into their privacy. In terms of AN, Minuchin et al. (1978) described a pattern of enmeshment in the families of patients with AN in which there is a general absence of generational or personal boundaries. Each family member is overinvolved in the life of every other family member to the extent that no one feels a separate sense of identity.

Studies on patients’ perspectives on the importance of receiving social support during the treatment process have also uncovered information about family dynamics. In their study of 40 women who recovered from BN, Rorty et al. (1993) found that while social support was seen as very helpful in treatment, parents were generally viewed as unhelpful. A substantial number of mothers (55%) and fathers (33%) were seen as being

actively harmful to the woman's recovery process (e.g., undermining the woman's efforts to get help). Similarly, Pettersen and Rosenvinge (2002) found in their mixed-methods study of 48 women that participants valued a distance from parents as helpful in recovery.

The prior discussion of patients' satisfaction with family therapy (p. 24-25) suggests that therapists can error by either blaming parents or by keeping the patient the sole focus of family meetings without challenging the parents to deal with their own issues. When the patient perspective studies are combined with the research on family dynamics in EDs as a whole, it can be inferred that patients want therapists to be competent in family dynamics.

Comparison to Therapists' Perspectives

Two studies have compared the views of patients and therapists on ED treatment. Vanderlinden et al. (2006) compared the views of 132 ED patients with 49 ED experts utilizing a questionnaire. The patients were recruited from inpatient and outpatient units offering CBT. The researchers found no major differences between the patients' and therapists' views. Both groups reported that improving self-esteem, improving body experience, and learning problems solving skills are core elements in ED treatment. There was one major difference: patients evaluated the support provided by the therapist as a more important treatment element than did therapists. Nevertheless, the researchers concluded that therapists and patients share more or less the same view about the basic and effective elements of ED treatment. De la Rie et al. (2008) compared the views of 73 therapists who treated patients with EDs to 156 current ED and 148 former ED patients. They found that both therapists and patients most often mentioned focus of treatment,

therapeutic alliance, and communication skills as important aspects of treatment. A major difference was that therapists valued the focus on ED symptoms and behavioral change more highly and patients valued the importance of the therapeutic relationship and addressing underlying problems more highly. The researchers concluded that for a therapist, a progressing patient is willing to work on behavioral change, whereas for a patient, a helpful therapist is understanding and willing to focus on the patient as a person. In conclusion, these two studies underscore that while therapists and patients generally have similar views on what constitutes effective ED treatment, patients value the importance of the therapeutic relationship more highly than do therapists. However, the results of these two studies are not representative of all people with EDs in the United States, as these studies took place in Belgium and the Netherlands.

Summary and Conclusions

In recent years, qualitative and quantitative studies with a range of ED populations have examined patients' perspectives on numerous elements of treatment, including: the therapeutic relationship, provision of social support, collaborative treatment, focus on emotions, focus on underlying issues, inclusion of psychoeducation, therapist's knowledge of EDs, behavioral interventions, appropriate use of medication, and therapist's competence in family dynamics.

The literature in this area has uncovered many treatment components that are favored by ED patients. First, by and large, the patient perspective literature has concluded that a solid therapeutic relationship is critical for recovery. ED patients have emphasized that an empathic, supportive, and understanding relationship is of utmost importance. Patients have noted that they highly value a therapist that they can trust and

who treats them with respect. Research has also found that the degree to which patients feel a sense of safety and acceptance in the therapeutic relationship either helps or hinders the recovery process.

Second, many studies have found that ED patients highly value social support. Patients have emphasized that support from family, friends, romantic partners, and fellow ED sufferers can be very helpful in the process of change. However, one study found that parents were generally viewed as unhelpful. Similarly, another study found that patients valued distance from parents as helpful in recovery. It seems that when parents are perceived as part of the problem, there needs to be a fundamental change in the family before they can be sources of support. Additional research should further investigate how patients feel about parental support in the treatment process.

Third, the patient perspective literature has found that patients prefer collaborative treatment approaches, in which they have a sense of control. Multiple studies have highlighted the need to incorporate patients' feedback on the process of treatment throughout recovery. Research has also discovered the importance of negotiating treatment goals with ED patients and suggests that when goals are unilaterally imposed by the therapist, satisfaction is much lower.

Fourth, patient perspective studies have discovered that patients find it important to address emotions in treatment. One study found that participants who maintained recovery attributed their success to having dealt with negative feelings, whereas participants who relapsed felt that the processing of core emotional issues was overlooked in treatment.

Fifth, research has also found that many ED patients find work on underlying issues, rather than exclusive attention to weight and eating behaviors, one of the most helpful aspects of treatment. Some researchers have concluded that addressing underlying issues is crucial in ED recovery. Future research should examine the specific types of underlying issues that patients find helpful addressing. Additionally, research should examine what specific therapeutic techniques are helpful for patients as they search for insight into their ED.

Sixth, the benefits of integrating psychoeducation in ED treatment have also been noted in the patient perspective literature. One study of women who recovered from BN found that psychoeducation was one of the most helpful components of treatment. Future research should investigate what specific educational information is helpful for patients in ED recovery.

The patient perspective literature has yielded mixed results with respect to several treatment areas. First, the literature on the importance of a therapist's knowledge of EDs has reported mixed reviews. Some studies have found that patients want therapists to have a solid working knowledge of EDs and think that there should be more specialists in the ED field. Two other studies found ambiguous results, with some patients reporting that specific knowledge about EDs is not vitally important. It appeared in some studies that therapists need to be knowledgeable about EDs in order to truly convey empathy and make patients feel understood.

Second, research on the use of behavioral interventions in ED treatment has found mixed results. Some participants have noted that behavioral interventions are helpful (e.g., learning distracting behaviors) while other patients have reported that behavioral

interventions are unhelpful or made their situation worse, particularly when the patient feels important issues are neglected. Much of the literature has found that patients negatively view behavioral interventions which focus exclusively on eating and weight. Additional research should investigate more closely the specific behavioral interventions that patients find helpful and unhelpful.

Third, the patient satisfaction literature has resulted in mixed reviews of the use of medication in ED treatment. Two studies found that patients viewed medication as helpful to some degree. Another study found that 50% of patients felt medication was helpful and 50% felt that medication was not helpful. Patients who expressed that medication was helpful reported that it helped them manage anxiety, depression, insomnia, and strong emotions.

From the research literature, an additional treatment element can be inferred: the need for the therapist to be competent in understanding family dynamics. One study of AN revealed that the most frequently mentioned causal factor of the ED was a dysfunctional family. Another study of AN found that patients feel that a serious error in psychotherapy is when therapists excessively blame parents for the ED. These studies highlight the importance of a therapist's competence in family dynamics and indicate that further research needs to be conducted in this area.

The patient perspective studies described in this review demonstrate that patients have rich and novel feedback for practitioners that can lead to more effective treatment. These studies have found that there is significant diversity in patients' perspectives on ED treatment. For example, Lemberg and May (1991), in their quantitative study of 28 ED patients, found that some of the therapies cited as *most helpful* by some patients were

cited as *least helpful* by others. These differences require that therapists work from a place of flexibility and evaluate and modulate treatment on an individual basis.

Treatment quality from the patient's perspective needs to be studied in order to improve the course of EDs and enhance recovery rates. While research in this field has expanded in recent decades, there is a need for additional studies in order to improve our understanding of the patient's experience in treatment. Overall, in the ED field, little attention has been paid to the personal perspective of patients on the factors that contribute to recovery (Tozzi et al., 2003). Expanding research in this area will increase our understanding of ED treatment and will greatly help with developing more effective treatments.

The literature on patients' perspectives on ED treatment, despite its limitations, offers a wealth of information that, when synthesized in a resource booklet, will contribute to the quality of practitioners' individualized treatment plans. To date, practitioners have little access to patients' views on what is helpful and not helpful in ED treatment. In particular, psychotherapists who work in private practice settings may not be aware of the valuable information that has been gained from ED patients. The resource developed from this literature review will introduce psychotherapists to patients' perspectives on various components of ED treatment and will, therefore, help practitioners develop more effective treatments.

Chapter III: Methodology

Introduction

The goal of this project was to develop a resource booklet for mental health professionals to guide them in their treatment of patients with EDs by focusing on patients' perspectives on what is helpful and not helpful in treatment. This chapter describes the method that was used to develop this resource. The first phase of the project involved an extensive review of existing literature and research studies to inform the content of the resource booklet, leading to a comprehensive summary chart provided in Appendix A. The second phase consisted of creating a category system from the literature for organizing the review and selecting the beneficial material for inclusion in the resource. The next phase was the creation of the resource booklet.

Identification of Relevant Literature and Existing Resources

Sources of data that were considered in the international and interdisciplinary review of literature were compiled from the following databases: PsycINFO, PsycARTICLES, MEDLINE, ProQuest, and Psychoanalytic Electronic Publishing. A search for books in print and internet resources was also conducted. In addition, information from national and international organizations was considered including publications from: the American Psychological Association, the American Psychiatric Association, the National Eating Disorders Association, the Academy for Eating Disorders, and the International Association of Eating Disorder Professionals. It was important to conduct a thorough and comprehensive search of presently available resources for psychotherapists in order to create a unique resource.

The literature review largely centered on topics and information related to patients' perspectives on EDs. Keyword combinations utilized in the search included the following:

- (eating disorders or anorexia nervosa or bulimia nervosa) AND (patient perspectives or client perspectives)
- (eating disorders or anorexia nervosa or bulimia nervosa) AND (patient attitudes or client attitudes)
- (eating disorders or anorexia nervosa or bulimia nervosa) AND (treatment satisfaction or patient satisfaction or client satisfaction)
- (eating disorders or anorexia nervosa or bulimia nervosa) AND (treatment variables or therapist variables)
- (eating disorders or anorexia nervosa or bulimia nervosa) AND (therapist characteristics or therapist role)
- (eating disorders or anorexia nervosa or bulimia nervosa) AND (clinical competence)
- (eating disorders or anorexia nervosa or bulimia nervosa) AND (practice guidelines)
- (eating disorders or anorexia nervosa or bulimia nervosa) AND (treatment outcome)

The articles acquired included both qualitative and quantitative studies. Additionally, articles involving inpatient and outpatient populations and any ED diagnosis were included.

In order to ensure the most comprehensive compilation of existing literature the following steps were also conducted. First, the reference lists of the articles found by the above means were searched in order to identify additional articles or books. Next, it was important to examine the keywords noted on these articles in order to determine if additional keywords needed to be utilized. Finally, Web of Science was utilized in order to find additional articles that had cited the articles located up to that point.

The last phase of the literature search involved the identification of experts in the field of patients' perspectives on ED treatment. Four experts met the criterion of having published two or more articles in this area. All experts were contacted by email in order to inquire about any unpublished articles and any suggestions they had pertaining to this project. (See Appendix B for an example of this email).

Target Audience

This resource was primarily designed for mental health professionals with an interest or specialty in working with individuals with EDs. The resource was geared toward professionals who work in outpatient settings, such as private practice offices and university student counseling centers, as well as for psychotherapy students with an interest in working with this population. Finally, the resource may be helpful for staff members (e.g., medical doctors, nurses, and nutritionists) at specialty service sites for patients with EDs.

Development of the Resource

The next phase of the project involved organizing and synthesizing all of the collected information into categories and topic areas based on common themes found in the literature review. A critical review and content analysis of the studies on patients'

perspectives on ED treatment was conducted, which led to the creation of a list of ten key treatment elements. First, the author developed a literature table that summarized the research studies on patients' perspectives (see Appendix A). Then, a list of all the terms and concepts that had been mentioned by patients in the studies was created, resulting in 55 items. Next, the author reviewed the list and created clusters of terms that fit together. For instance, the terms empathy, support, respect, understanding, and seeing the person beyond the symptoms were combined under the more abstract concept *the therapeutic relationship*. Using this method, a list of 9 elements was constructed. With further examination, and consultation with colleagues and dissertation committee members, the list was modified, resulting in 10 categories. Nine of the categories came directly from the literature; the tenth (Therapist's Competence in Family Dynamics) evolved by revisiting the other categories and drawing inferences from the patient comments about parents, etiology, family dysfunction, and the negative effect of ignoring the parents' problems. The list of ten elements was organized in order of descending importance. These categories were then used as topic headers in Chapter II and in the resource booklet.

Format and structure of resource. The length of the resource was intended to be approximately 30-35 pages. The booklet contains three major sections. Part I: General Information includes the following subsections: (a) Highlights in the Historical Review of Eating Disorders, (b) Eating Disorder Diagnoses, (c) Statistics on Eating and Body Image Problems, (d) Cultural Diversity, (e) Etiological Theories, and (f) Treatment Options.

Part II: Patients' Perspectives on Eating Disorder Treatment includes the following subsections: Overall Treatment Satisfaction; Treatment Modalities; Ten Treatment Elements: (a) The Therapeutic Relationship, (b) Provision of Social Support, (c) Collaborative Treatment, (d) Focus on Emotions, (e) Focus on Underlying Issues, (f) Inclusion of Psychoeducation, (g) Therapist's Knowledge of Eating Disorders, (h) Behavioral Interventions, (i) Appropriate Use of Medication, (j) Therapist's Competence in Family Dynamics; Table: Research Studies on Patients' Perspectives; Limitations; Recommendation to Practitioners.

Part III: Additional Resources includes the following subsections: (a) Eating Disorder Organizations, (b) Helpful Websites, (c) Books for Patients and Professionals, (d) Books for Professionals, (e) References.

Content of resource. The following is a more detailed description of the three sections included in the resource:

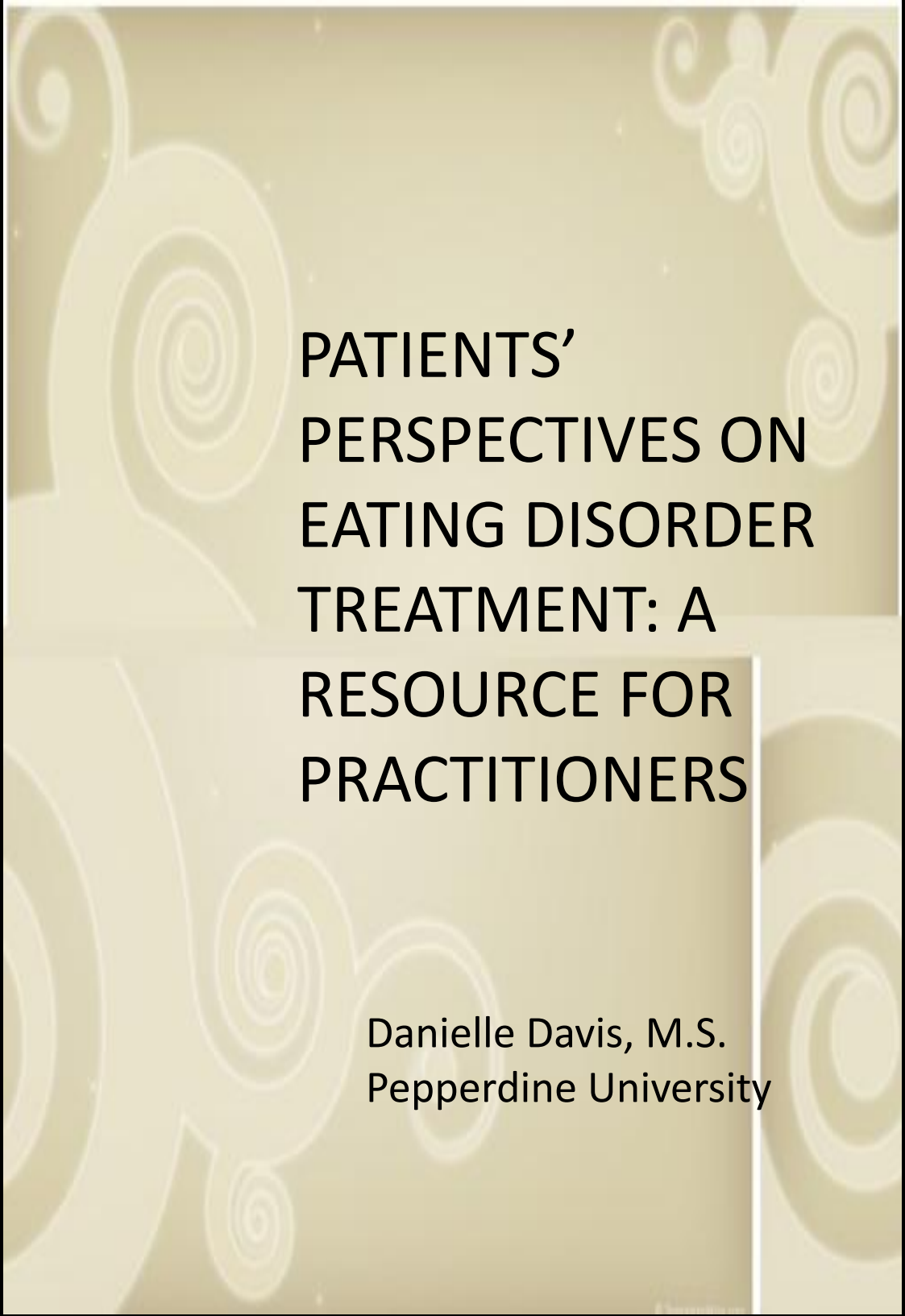
Part I consists of general information on EDs. Information on the history of ED diagnosis is provided along with the current diagnostic criteria for each of the three ED diagnoses. This section also includes a variety of statistics on eating and body image problems from a range of sources. Information on cultural diversity, specifically, ethnic, age, and gender diversity in EDs, is provided. Then, an overview of etiological theories is given. Finally, a review of the current treatment options (e.g., CBT and psychodynamic treatments) available to clinicians treating ED patients is included.

Part II includes information on patients' perspectives on ED treatment, the focal point for this project. This section begins with information on overall treatment satisfaction, followed by information on treatment modalities (i.e., individual, family, and

group therapy). Then, the ten key treatment elements are listed. Each treatment element is described within one to two pages. Following the ten treatment elements, a chronological table of the studies on patients' perspectives on ED treatment is included. This table indicates which treatment element(s) each study investigated. Then, a discussion of the limitations of the research on patients' perspectives is provided. Last, recommendations to practitioners who utilize this resource are included.

Part III includes information on additional resources that practitioners may find helpful in their treatment of patients with EDs. This section includes information on several ED organizations and provides addresses for helpful websites. In addition, multiple books on EDs for patients and professionals are described. Finally, a reference list is provided to help readers identify literature of interest to them.

Chapter IV: Resource Booklet



**PATIENTS'
PERSPECTIVES ON
EATING DISORDER
TREATMENT: A
RESOURCE FOR
PRACTITIONERS**

Danielle Davis, M.S.
Pepperdine University

Introduction

Eating Disorders (EDs) can be devastating to the lives of people who suffer from them. They can affect all areas of a person's functioning, including emotional wellbeing, social relationships, occupational functioning, and physical health. According to The National Eating Disorders Association (2006), as many as 10 million females and 1 million males are suffering from EDs in the United States. The number of people with EDs has also been increasing since their recognition, paralleling society's growing obsession with being thin (Costin, 2007).

Many practitioners report that patients with EDs are difficult to treat. A better understanding of the factors that contribute to this difficulty could help improve treatment outcome. Treatment outcome studies indicate that there is a great need to increase treatment success and that many patients are dissatisfied with ED treatment. Patient satisfaction plays a central role in the therapeutic alliance and treatment outcome. It is important to listen to patients' perspectives about what works and what does not work in treatment. The purpose of this resource booklet is to provide practitioners with a synthesis of all of the studies that have been conducted on patients' views of ED treatment. This booklet is designed to be a resource for practitioners to help guide them in their treatment of patients with EDs. It is based on the author's comprehensive review of the literature in this field.



This project is in partial fulfillment of the requirements for the Psy.D. degree at Pepperdine University.

Disclaimers

- This resource booklet is aimed at helping practitioners who work with ED patients on an outpatient basis. It provides information from research on groups of people and shows both consensus and individual differences. Clinicians will not find general rules that apply to all patients, but will gain a knowledge base that will help in individualizing treatment and understanding what input to seek from each patient.
- The information provided in this booklet is not sufficient to gain a complete understanding of ED treatment. Readers who are interested in a comprehensive review of ED treatment should consult *The American Psychiatric Association's Practice Guidelines for the Treatment of Patients with Eating Disorders, Third Edition* (2006) or books that provide comprehensive information on treatment, such as *Effective Clinical Practice in the Treatment of Eating Disorders: The Heart of the Matter* (2009).
- There are limitations to the studies that have been conducted on patients' perspectives. These limitations are reviewed on page 47. This resource is only as strong as the literature in this field, therefore these limitations apply to this booklet as well.

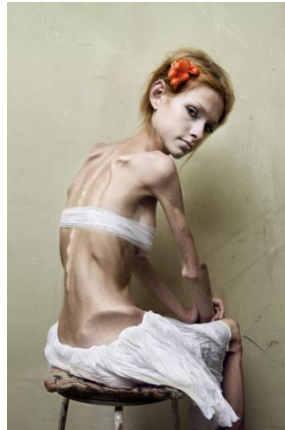


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Part I: General Information

4

Highlights in the Historical Review of Eating Disorders

- The first medical account of what we know today to be Anorexia Nervosa (AN) was described by Richard Morton, an English physician, in 1689 (Silverman, 1997).
- Ernest-Charles Lasègue of Paris and Sir William Gull of London, prominent physicians, gave the first explicit descriptions of AN (Vandereycken, 2002a).
- In 1873, Lasègue published an article, *On Hysterical Anorexia*, shortly before Gull presented case reports utilizing the term “anorexia nervosa” (Silverman, 1997).
- In many countries, including the United States, AN remained a marginal phenomenon until well into the 20th century (Vandereycken, 2002a).
- In 1903, Bulimia Nervosa (BN) was first described in medical terms in *Obsessions et la Psychasthenie* by psychiatrist Pierre Janet (Costin, 2007).
- In 1944, the Swiss psychiatrist Ludwig Binswanger published the most carefully documented case report on BN (Vandereycken, 2002a).
- In 1973, Hilde Bruch introduced the first major book in the field, *Eating Disorders: Obesity, Anorexia Nervosa, and the Person Within*.
- In 1978, Bruch’s pioneering book, *The Golden Cage: The Enigma of Anorexia Nervosa*, raised awareness of EDs among the general public.
- In 1979, Gerald Russell, a British psychiatrist, coined the term Bulimia Nervosa (Vandereycken, 2002a).
- In 1992, the term Binge-Eating Disorder (BED) was introduced in the *International Journal of Eating Disorders* (Costin, 2007).



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Eating Disorder Diagnoses

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) includes three diagnoses for EDs: Anorexia Nervosa (AN), Bulimia Nervosa (BN), and Eating Disorder Not Otherwise Specified (ED-NOS; American Psychiatric Association, 2000, p. 583). Here is the specific criteria for each diagnosis:

307.1 Anorexia Nervosa

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

Specify type:

Restricting Type: During the current episode of AN, the person has not regularly engaged in binge-eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

Binge-Eating/Purging Type: During the current episode of AN, the person has regularly engaged in binge-eating or purging behavior (e.g. self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

Eating Disorder Diagnoses

307.51 Bulimia Nervosa

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 (e.g., within any 2-hour period), 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 (e.g., a feeling that one cannot stop eating or control what or how much one is eating)

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 AN.

Specify type:

Purging Type: During the current episode of BN, the person engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.

Nonpurging Type: During the current episode of BN, the person has used other inappropriate compensatory behaviors, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.

Eating Disorder Diagnoses

307.50 Eating Disorder Not Otherwise Specified

The ED-NOS category is for disorders of eating that do not meet the criteria for any specified ED. Examples include:

1. For females, all the criteria for AN are met except that the individual has regular menses.
2. All of the criteria for AN are met except that, despite significant weight loss, the individual's current weight is in the normal range.
3. All of the criteria for BN are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week 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 (e.g., self-induced vomiting after the consumption of two cookies).
5. Repeatedly chewing and spitting out, but not swallowing, large amount of food.
6. Binge-eating disorder (BED): Recurrent episodes of binge eating in the absence of the regular use of inappropriate compensatory behaviors characteristic of BN (see p. 785 of DSM-IV-TR for suggested research criteria for BED).



DSM-V Eating Disorder Classifications

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V), is expected in 2012. The DSM Eating Disorders Work Group is considering several issues relating to ED diagnoses. In April 2009, an article was published in the *Monitor on Psychology* describing these issues. Here are some of the key points from that article:

- The group is considering whether to create new ED diagnoses or to allow more flexibility in the current diagnostic criteria (DeAngelis, 2009). For example, the group is considering removing amenorrhea from the AN criteria as many practitioners report that some females do not experience a loss of their period and this criteria does not apply to males.
- The group is also exploring the ED-NOS diagnosis. Researchers estimate that 60-65% of ED diagnoses fall in this category (DeAngelis). Dr. Timothy Walsh of Columbia University, the work group chair, stated that, “when the default diagnostic criteria is your primary category, that’s a problem” (p. 45).
- The group is considering making binge-eating disorder (BED) an official diagnosis (DeAngelis). Currently, BED is described in the section on diagnoses for future research in the back of the DSM. In the DSM-IV, the diagnosis of BED officially belongs in the broad ED-NOS category.
- The group is also examining how to classify EDs in children, how to address the cultural impact on EDs, and how to define a *binge* (DeAngelis).



Statistics on Eating and Body Image Problems

- 81% of 10-year-olds are afraid of being fat (Mellin et al., 1991).
- 40% of newly identified cases of AN are in girls 15-19 years old (Hoek and van Hoeken, 2003).
- Most fashion models are thinner than 98% of American women (Smolak, 1996).
- AN has the highest premature fatality rate of any mental illness (Sullivan, 1995).
- While EDs are more common than Alzheimer's disease, funding for ED research is approximately 75% less than that for Alzheimer's disease (NEDA, 2006).
- Only 6% of people with BN receive mental health care (Hoek & van Hoeken).
- Only 1/3 of people with AN in the community receive mental health care (Hoek & van Hoeken).
- Girls who diet frequently are 12 times as likely to binge as girls who don't diet (Neumark-Sztainer, 2005).
- 95% of all dieters will regain their lost weight in 1-5 years (Grodstein, Levine, Spencer, Colditz, & Stampfer, 1996).
- Long-term follow-up studies of AN indicate that nearly 50% eventually make a full recovery, 20-30% show residual symptoms, 10-20% remain severely ill, and 5-10% die of related causes (Steinhausen, 2002).
- For patients with BN, estimates of remission over time range from 31 to 74%; however, remission is often fleeting and relapse is common (Wilson, Grilo, & Vitousek, 2007).

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Cultural Diversity

It is often assumed that EDs are only a problem for young, white females. However, EDs are on the rise in various populations. Body image and eating problems appear in every economic and ethnic group of American culture and in at least 40 countries worldwide (Gordon, 2000).

Ethnic Diversity

Numerous studies in the United States have investigated the prevalence of EDs in various ethnic groups.

- Racial differences in EDs are reported throughout the literature, including the finding that bulimic symptoms are less common among many minority groups (Lokken, Worthy, Ferraro, & Attman, 2008). Research indicates that BN is significantly less prevalent among black women than white women (Striegel-Moore et al., 2003).

Note: Some researchers have argued that the presence of EDs in minorities is underestimated for a variety of reasons, including lack of recognition by health care providers and poor access to health care services (Franko et al., 2004).

- Studies of EDs in Asian populations have yielded different findings. Some studies indicate that there is no difference in the prevalence of EDs in Asian populations compared to other ethnic groups (Gross & Rosen, 1988; Cachelin, Veisel, Barzegarnazari, & Striegel-Moore, 2000; Le Grange, Stone, & Brownell, 1998). Other studies provide preliminary evidence for higher rates of certain ED symptoms, such as body dissatisfaction, in Asian-American populations (Robinson et al., 1996; Story, French, Resnick, & Blum, 1995).
- Researchers have also investigated the prevalence of EDs in Latino populations. One study in northern California found that Hispanic girls were more likely to experience body dissatisfaction than their Caucasian peers in a group of the lowest weight girls (Robinson et al., 1996). Unfortunately, EDs often go unrecognized in ethnic minorities or are only acknowledged once they have progressed to a more severe stage (Cummings, Simmons, & Zane, 2005).

Cultural Diversity

Age Diversity

The prevalence of EDs amongst people in midlife is also a growing area of concern.

- In the past ten years, psychologists across the nation have reported a startling rise in the number of midlife women seeking treatment for eating problems (Bulik & Taylor, 2005). Costin (2007) reported that body dissatisfaction in midlife has increased dramatically, more than doubling from 25% in 1972 to 56% in 1997.

Recommendation: A helpful book on eating and body image issues during midlife is *Runaway Eating* by Cynthia Bulik, Ph.D. (a leading ED expert) and Nadine Taylor, M.S., R.D. See "Additional Resources" for more information.



Cultural Diversity

Gender Diversity

EDs in the male population are also receiving growing attention.

- There has been a gradual increase in the number of men suffering from AN or BN over the past two decades from 1 in 20 cases to possibly 1 in 12 (Maine, 2000).
- Researchers at Lucile Packard Children's Hospital and the Stanford University School of Medicine say that physicians often overlook EDs in boys because they are used to diagnosing girls (Anonymous, 2007).
- While the number of males suffering from AN and BN is far less than female, 40% of the cases of BED are male (Costin, 2007).
- Research has also found that there is a higher prevalence of EDs in gay and bisexual men than heterosexual men (Feldman & Meyer, 2007).
- Men are increasingly being exposed to the muscular ideal as the preferred body type.

Recommendation: An excellent book on this topic is *The Muscular Ideal* published by the American Psychological Association. See "Additional Resources" for more information.



Etiological Theories

In this section, an overview of current etiological theories will be given. The research on the etiology of EDs indicates that risk for EDs is multifactorial and there is more than one pathway toward the development of an ED. That is, EDs are multidetermined and no one theory is sufficient to explain an ED in a given person.

Biological Theory

It has long been understood that EDs tend to run in families. Research has demonstrated that an individual has a higher risk of developing an ED if a relative has one and an even higher risk if it is a first-degree relative (Costin, 2007). However, it is difficult to separate biological factors from environmental factors because they are always interacting. Twin studies have found that the concordance rates are substantially greater for monozygotic twins than for dizygotic twins, indicating a strong etiological role for genetic factors (Strober & Bulik, 2002). While there is evidence that genetic differences explain a portion of the presence of an ED, this does not mean that all EDs are caused by genetic factors or that the environment is irrelevant (Costin).



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Etiological Theories

Sociocultural Theory

Sociocultural influences have a significant role in promoting disturbances of body image and eating. With respect to media influence, studies have shown that 60% of Miss America contestants and 25% of the models in some magazines are 85% or less than their ideal body weight, meeting one of the diagnostic criteria for AN (Maine, 2000; Stice, 2002). This trend toward excessive thinness correlates positively with the rise in EDs and suggests that the media contributes to disordered eating. There is also growing support that sociocultural pressures from peers contribute to body image disturbance and disordered eating. Perceived peer interest in dieting and the thin-ideal have been found to correlate positively with eating pathology (Stice).



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Etiological Theories

Sociocultural Theory (Continued)

Sociocultural pressures center around the idealization of thinness and the denigration of people who are perceived as *overweight*. Social learning theorists describe two processes which promote specific attitudes and behavior:

Social Reinforcement And Modeling

Through social reinforcement, people internalize attitudes and exhibit behaviors approved of by respected others (Stice, 2002). In the domain of EDs, social reinforcement is delivered by verbalization or actions of others that support the thin-ideal body image.

Example: An adolescent female who perceives that society glorifies thinness may be more likely to pursue a slender physique.

Through modeling, people observe others, form an idea of how new behaviors are performed, and then this coded information serves as a guide for action (Bandura, 1977).

Example: An adolescent male who sees his peers engage in excessive exercise may be more likely to engage in this behavior.

Etiological Theories

Cognitive-Behavioral Theory

The essence of cognitive-behavioral theory is that feelings and behaviors are created by thoughts. According to cognitive-behavioral theory, the core disturbance amongst ED patients is a characteristic set of thoughts associated with the desire to control eating and weight. A fundamental premise is that self-worth is represented in the size and shape of the body (Vitousek, 2002). Instead of evaluating self-worth on the basis of performance in a multitude of domains, such as work, artistic ability, and interpersonal relationships, people with EDs evaluate themselves primarily in terms of their eating, shape, and weight (Fairburn, 2002).

According to cognitive-behavioral theory, patients with EDs engage in cognitive disorders, such as:

- overgeneralizing
- assuming
- magnifying or minimizing
- personalizing
- magical thinking
- all-or-nothing thinking

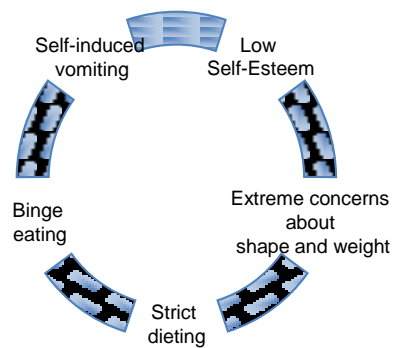
A distorted body image, paranoia about all food being fattening, and bingeing based on the belief that eating one *bad* food destroyed a perfect day of dieting are common cognitive distortions among people with EDs (Costin, 2007).

Example: If a woman does not trust herself to make decisions, all-or-nothing thinking provides a strict system of rules for her to follow.

Etiological Theories

Cognitive Behavioral Theory (Continued)

In terms of BN, the following causal sequence has been described: (a) low self-esteem, (b) extreme concerns about shape and weight, (c) strict dieting, (d) binge eating, and (e) self-induced vomiting (Fairburn, Marcus, & Wilson, 1993). In turn, purging helps maintain binge eating by reducing anxiety about weight gain and disrupting learned satiety that regulates food intake (Wilson, Fairburn, & Agras, 1997).



In terms of AN, cognitive behavioral theory describes that these patients engage in stereotypical eating and elimination behaviors in order to increase their self-worth (Vitousek, 2002). These behaviors are then maintained in that AN patients often report that their self-esteem improved after they lost weight (Garner, Vitousek, & Pike, 1997).

Etiological Theories

Psychodynamic Theory

Psychodynamic theories on the etiology of EDs emphasize internal conflicts, early relationships, and unconscious forces. In psychodynamic theory, symptoms are seen as expressions of a struggling inner self that uses disordered eating and weight control behaviors as a way of communicating underlying issues (Costin, 2007). The symptoms of an ED can be:

- Symbolic expressions of psychic aims and defenses
= drive-conflict model
- Symbolic expressions of distorted self and object representations
= object-relations model
- Nonsymbolic measures used to stem the tide of disrupted self-states threatened with the loss of cohesion of the self
= self-psychological model

In one study of BN, researchers found that there were disturbances in the emotional dialogue between BN patients and their parents (Reich & Cierpka, 1998). The authors of this study speculate that the patient's conflicting identifications with the parents resulted in a consistent pattern of conflict between contradictory parts of the self. They also described that many BN patients experience a lack of respect for boundaries, such as a tactless intrusion into their privacy.



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Etiological Theories

Psychodynamic Theory (Continued)

With respect to AN, Bromberg (2001) suggested that these patients transform desire into renunciation through the mechanism of dissociation. The person with AN dissociates into separate self states as a way to wall off traumatic experiences and to promote maximal functioning uncontaminated by her intense affects. The patient lacks a form of human relatedness that allows her to develop self-regulation of affect states and, therefore, cannot contain desire long enough to make reasonable choices. Parents of AN patients may have been incapable of validating the separate sense of self of their children, and instead may have used them to meet their own needs for soothing and validation. As a result, the patient cannot rely on others to meet her needs and may engage in starvation as a desperate attempt to gain attention.



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Etiological Theories

Psychodynamic Theory (Continued)

Attachment disturbance has also been described as leading to an ED later in life. Attachment theory describes the process of bonding between caregiver and infant, and the consequences to the infant of the disruption of that bond. Pearlman (2005) described that when an infant is chronically unable to find an attuned emotional connection to her mother, she may attempt to comfort herself from anxiety through thumb or pacifier sucking or demands for food. Pearlman explained that these self-regulatory mechanisms can become imprinted as the primary means of self-care, replacing human attachment, and this process can lead to the development of an ED.



Early attachments disruptions can also explain why EDs are often triggered by experiences of separation and loss, such as puberty, moving away to college, or ending a romantic relationship.

Etiological Theories

Family Systems Theory

Specific family dynamics have also been described in the literature on the etiology of EDs. Minuchin, Rosman, and Baker (1978) described a pattern of enmeshment in the families of patients with AN in which there is a general absence or lack of generational or personal boundaries. Each family member is overinvolved in the life of every other family member to the extent that no one feels a separate sense of identity. Similarly, the parents of children who grow up to suffer from BN often relate to their children as extensions of themselves (Gabbard, 2005). These children are often used to validate the self of the parent, and each member of the family depends on all the other members to maintain a sense of cohesion (Gabbard).



Parental pressure to lose weight and family criticism regarding weight are positively correlated with adolescent eating disturbances (Stice, 2002).

Treatment Options

This section includes an overview of the major ED treatment approaches.

Multidisciplinary Treatment

Because of the complex nature of EDs, a multidisciplinary approach to treatment is highly recommended (Kaplan, 2002).

The Treatment Team

1. **Psychotherapist:** The treatment team should include a psychotherapist who has experience working with patients with EDs and is trained in treatments known to be effective with this population.
2. **Psychiatrist:** A psychiatrist who has experience with the medical management of patients with EDs should also be involved.
3. **Nutritionist:** Nutritionists play a key role in the multidisciplinary treatment of patients with EDs.

Treatment providers also need to consider what level of care is appropriate for each patient. Treatment can range from intensive inpatient programs to residential and partial hospitalization programs to varying levels of outpatient care (APA, 2006). It is important to note that this booklet is designed for outpatient therapists and does not address the needs of patients in more intensive settings.



Treatment Options

Nutritional Rehabilitation

For patients with AN, nutritional rehabilitation is of utmost importance. For patients who are markedly underweight and for children and adolescents whose weight has deviated below their normative growth curves, hospital-based programs for nutritional rehabilitation need to be considered (APA, 2006).



At the same time, clinicians are in agreement that treatment goals for patients with AN must not be focused narrowly on weight gain (Gabbard, 2005).

Treatment Options

Cognitive-Behavioral Therapy

For BN, cognitive-behavioral therapy (CBT) is the leading evidence based treatment and is considered the *gold-standard* among many experts in the field (APA, 2006; Costin, 2007). CBT is also used for patients with AN, although the empirical validation is not as strong as for BN and there is a need for further research in this area.

The leading CBT treatment manual for BN was published by Fairburn, Marcus, and Wilson in 1993

- This program consists of 19 sessions of individual therapy over 20 weeks.
- The treatment is problem-oriented and primarily based on the present and future.
- The first stage involves psychoeducation and helping the patient to start regaining control over eating. This stage includes learning self-monitoring, self-control strategies, and conducting weekly weighing.
- The second phase involves an emphasis on regular eating, specifically 3 meals and 2 snacks per day, and addressing the overevaluation of shape and weight. At this point, cognitive distortions are challenged and the patient begins to learn problem solving techniques.
- The final phase involves setting realistic expectations and making a plan for how to deal with set backs.

Treatment Options

Psychodynamic Therapy

The value of psychodynamic treatments for EDs has also been clearly described and may be recommended on clinical grounds when short-term treatments are ineffective (Garner & Needleman, 1997).

- The common feature of all psychodynamic theories of EDs is the belief that if the underlying causes of disordered behaviors are not addressed, they may subside for a time but will often return (Costin, 2007).
- The goal of this treatment approach is to help patients understand connections between their past and their personal relationships, and how they relate to their ED.
- Psychodynamic therapy with AN patients often takes several years of work because of the formidable resistance posed by the patient (Gabbard, 2005). During this process, it is important to avoid excessive investment in trying to change the eating behavior, avoid interpretations early in therapy, and carefully monitor countertransference.



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Treatment Options

Psychodynamic Therapy (Continued)

Pearlman (2005) wrote about ED treatment considerations from an attachment perspective. She explained that many professionals and parents focus narrowly on the symptoms of purging and weight gain or loss, and thereby reinforce the patient's substitution of symptom for relatedness. Pearlman described that it is important for professionals, and if possible parents, to be patient and to not attempt to control the patient's feelings or symptoms as a way of containing their own anxiety. She described that this approach can contribute tremendously to the success of treatment by not recreating a misattuned pattern of caretaking.

Interpersonal psychotherapy (IPT), a modified form of psychodynamic therapy, is another treatment used for patients with EDs. IPT is designed to help people identify and address current interpersonal problems. A novel aspect of IPT for BN is the evaluation of possible interpersonal triggers of individual episodes of binge eating, as binges are commonly precipitated by interpersonal events (Fairburn, 2002).



Treatment Options

Family Therapy

In the field of EDs, there is an acceptance of a problem in the functioning of the families of these patients, and hence an acknowledgment of a possible place for family interventions (Dare & Eisler, 1997).

- Family therapy is the treatment of choice for AN patients who are 18 years old or younger and live at home (Garner & Needleman, 1997).
- In family therapy for AN, there is a strong focus on helping parents manage their child's symptomatic behavior.
- The therapist helps the parents overcome their sense of helplessness and leads them to find a way of mobilizing the family's resources (Dare & Eisler, 2002).
- As treatment progresses and the patient gains weight, therapy involves a discussion of wider family issues, an exploration of the patient's feelings and beliefs about her problems, body image, and self-esteem (Dare & Eisler).




Treatment Options

Integrative Therapy

Many practitioners in the field of EDs chose to use an integrated treatment approach. In general, there is a movement in the field of psychotherapy toward eclecticism and integration of different therapeutic approaches (Garfield, 1994). The wisdom of integrating psychotherapeutic interventions is increasingly evident with the demonstrated effectiveness of different forms of treatment (Garner & Needleman, 1997).

The American Psychiatric Association's Practice Guidelines for the Treatment of Patients with Eating Disorders, Third Edition (2006) states that using psychodynamic interventions in conjunction with CBT and other psychotherapies may yield better global outcomes than CBT alone in the treatment of patients with BN.





**Part II:
Patients' Perspectives
on Eating Disorder
Treatment**

30

Introduction

Since the 1980s, patients' perspectives on the treatment of EDs has been receiving growing attention. Qualitative and quantitative studies with a variety of ED populations have been conducted around the world. Researchers have asked patients about their views on a multitude of treatment components. In this section, information about patients' overall treatment satisfaction will be provided, followed by patients' views on the helpfulness of different treatment modalities (i.e., individual therapy, family therapy, and group therapy). Then, patients' perspectives on 10 treatment elements will be presented. These 10 categories were created from the authors critical review of the studies in this field.

10 Treatment Elements

The Therapeutic Relationship
Provision of Social Support
Collaborative Treatment
Focus on Emotions
Focus on Underlying Issues
Inclusion of Psychoeducation
Therapist's Knowledge of Eating Disorders
Therapist's Competence in Family Dynamics
Behavioral Interventions
Appropriate Use of Medication

Overall Treatment Satisfaction

Studies on overall treatment satisfaction from the patient's perspective have yielded varied results.

- One of the first studies on treatment satisfaction was conducted in the United States utilizing an advertisement in *Glamour Magazine* (Yager, Landsverk, & Edelstein, 1989). This study found that respondents generally felt that professional treatment only helpful them *a little*.
- Other studies have found that patients are more satisfied with treatment. A study of AN patients in the United Kingdom found that 33.3% of participants felt that treatment was helpful, 33.3% felt that treatment was mixed helpful and unhelpful, and 19.5% felt that treatment was unhelpful (Button & Warren, 2001).
- A study in New Zealand of patients who underwent a hospital-based inpatient treatment program, found the greatest satisfaction, with 75% of respondents endorsing that treatment was either good or excellent (Swain-Campbell, Surgenor, & Snell, 2001).
- Many studies have found that patients feel there were negative effects of ED treatment. Patients report negative experiences when they do not have control over the treatment process, such as with treatments that focus exclusively on weight. A Canadian study of AN patients found that the majority of patients perceived treatment as traumatic and defined recovery to some extent on their ability to *survive* treatment (Weaver, Wuest, & Ciliska, 2005).

There is a great need to improve treatment satisfaction. One pathway toward that goal is to better understand what elements of treatment patients find helpful and not helpful.

Treatment Modalities

Numerous studies have examined patients' satisfaction with different types of treatment modalities (i.e., individual, family, and group therapy)

- Several of these studies have found that individual therapy is seen as widely helpful.
- In one study of AN patients, researchers found that individual therapy was by far seen as the highest rated of all treatments (Beresin, Gordon, & Herzog, 1989). One participant in this study expressed:

“I feel as though I was raised again from infancy, building a sense of myself” (p. 114).

- Studies that have inquired about patients' satisfaction with family therapy have yielded mixed results.
- One study of AN patients found that 12% of participants felt that family therapy was of great help, 53% felt that it was of some help, and 35% felt that it was of no help (Paulson-Karlsson, Nevonon, & Engström, 2006).
- In a final study of over 300 patients with a variety of ED diagnoses it was found that participants were highly satisfied with outpatient individual and group psychotherapy, and to a less extent with family therapy (Rosenvinge & Klusmeier, 2000).
- There is a need for more studies on patients' experiences with group therapy.



10 Treatment Elements

#1 The Therapeutic Relationship

The vast majority of studies on patients' perspectives on EDs have emphasized the importance of a strong therapeutic relationship.

- *Understanding* is seen as a very important therapist quality. One study with over 300 participants found that was the *understanding* most frequently identified helpful therapist quality and it was rated far more important than *knowledge of EDs* (Rosenvinge & Klusmeier, 2000).
- In a study of female ED patients, Pettersen and Rosenvinge (2002), found that treatment satisfaction was strongly associated with experiencing a therapeutic relationship which emphasized:

Support, Empathy, Respect, Understanding,
and Seeing the Person Beyond the Symptoms

- In another study of over 300 participants, De la Rie, Noordenbos, Donker, and van Furth (2008), found that 5 of the 10 most important criteria of quality treatment involved the therapeutic relationship:

#1 Trust in therapist
#2 Being taken seriously
#3 Treatment that addressed the person
#6 Being respected
#10 Being accepted as you are

10 Treatment Elements

#1 The Therapeutic Relationship

Why is the therapeutic relationship so important to patients with EDs?

- Patients with EDs may stress the importance of a good therapeutic relationship because they find it particularly challenging to engage in a relationship with the therapist (De la Rie et al., 2008).
- This difficulty may be due to early life experiences when mental representations about oneself in relationship with others are formed (De la Rie et al.).
- From an attachment theory perspective, ED patients have an intense fear of forming attachment, including therapeutic attachments (Pearlman, 2005).
- ED patients may unconsciously resist relating to a therapist because of their fears of annihilation stemming from early infant trauma (Pearlman).



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10 Treatment Elements

#2 Provision of Social Support

Research has found that people with a history of an ED feel that it is very important to have supportive relationships while in recovery.

- Studies have shown that receiving help from friends, family, or a romantic partner is very helpful.
- Pettersen and Rosenvinge (2002) found that ED patients described that:

“Important individuals were often the first to know about their problems, the first to encourage them to seek professional help, and the main source of trust, acceptance, and practical and emotional support” (p. 67).



- Another study of women who recovered from BN found that parents were generally viewed as unhelpful (Rorty, Yager, & Rossotto, 1993). A substantial number of mothers and fathers were perceived as being harmful to the recovery process (e.g., blaming the woman for having the disorder or undermining her efforts to get help).
- Several studies have also found that ED patients find it very helpful to receive support from other ED sufferers. One study found that meeting with other sufferers promoted a feeling of being able to recognize oneself in others, helped patients realize their own potentials, and provided hope with respect to recovery (Pettersen & Rosenvinge, 2002).

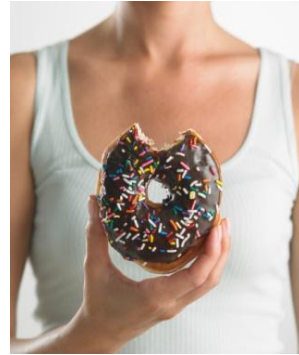
10 Treatment Elements

#3 Collaborative Treatment

Multiple studies have found that patients respond well to a collaborative treatment approach in which they have some control over the process. Patients want therapists to seek and incorporate their input throughout treatment.

- In a study of patients with AN, Button and Warren (2001) found a common theme:

Patients felt their ED had been a response to a sense of loss of control in one or more areas of their lives.



The authors of this study recommend that therapists take into account the patient's high level of need for control.

- Another study found that it is important to negotiate treatment goals with ED patients at different moments during the process of change and this extent to which this occurs may explain differences in treatment satisfaction (De la Rie, Noordenbos, Donker, & van Furth, 2006).
- Another study found that for AN patients a positive experience of treatment involved the patient participating in treatment planning and agreeing on the content of treatment (Paulson-Karlsson et al., 2006).

10 Treatment Elements

#4 Focus on Emotions

Several studies have found that patients think it is important for therapists to help them identify, process, and manage emotions.

- In a study of women who recovered from AN, patients expressed that therapy helped to introduce them to feelings, to learn why they felt guilty, and to realize that anger cannot destroy the person it is aimed at (Beresin et al., 1989).
- In a study of 21 ED patients who received CBT, dissatisfied patients reported that their personal problems and feelings were not dealt with sufficiently (Le Grange & Gelman, 1998). One participant in this study specifically stated that treatment neglected to deal with the *emotional side* of the ED.
- In a study of people who weight-recovered from AN, it was found that patients who later relapsed felt that the identification and processing of core emotional issues were overlooked in treatment (Federici & Kaplan, 2008). The participants felt that they were left vulnerable and unskilled in managing ongoing emotional stressors. On the other hand, participants who maintained a healthy weight attributed their success to having dealt with negative feelings. One participant expressed:

“I am able to tolerate negative emotions and that has had a very positive influence on my staying well...on my getting recovered and maintaining it. So, the negative emotions...I’m totally able to feel them and not get overwhelmed by them and not have them translate into negative behaviors...that’s fundamentally important” (p. 6)!

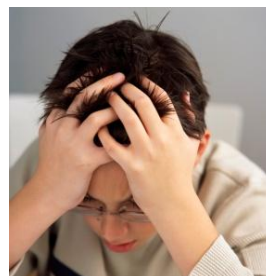
10 Treatment Elements

#5 Focus on Underlying Issues

Research has found that ED patients find it helpful to address issues underlying an ED. Patients have expressed that gaining insight into their ED and understanding the meaning of the ED in their daily life is very important in treatment (Vanderlinden, Buis, Pieters, & Probst, 2007).

- In a study of patients with BN, participants expressed that one of the most helpful aspects of treatment was work on underlying issues and it was concluded that addressing underlying issues is crucial in recovery (Rorty et al., 1993).
- Another study found that highly valued components of treatment for ED patients were a better understanding of their situation and help to deal with issues underlying the ED (Pettersen & Rosenvinge, 2002).
- In a study of women who weight-recovered from AN, researchers found that participants who relapsed felt that the issues underlying their ED were not adequately addressed in treatment (Federici & Kaplan, 2008). One patient expressed:

“I feel like I didn’t deal with any of the issues that were there to begin with. The bereavement, the self-esteem issues...I hadn’t dealt with why I had this eating disorder. How can I fix something when I don’t even know what the cause of it is” (p. 5)?



10 Treatment Elements

#6 Inclusion of Psychoeducation

Three studies have found that patients feel it is helpful to include psychoeducation in treatment.

- In a study of patients with BN, participants reported that receiving education about EDs was one of the most helpful treatment experiences (Rorty et al., 1993).
- In a study of 21 ED patients who received CBT treatment, 1/3 of the participants felt that receiving information about EDs was helpful (Le Grange, 1998).
- In a study of people who weight recovered from AN, patients reported that specific interventions, such as psychoeducation, were essential components of recovery (Federici & Kaplan, 2008).



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10 Treatment Elements

#7 Therapist's Knowledge of Eating Disorders

Researchers have also looked at patients' views on the importance of a therapist's knowledge of EDs. These studies have yielded somewhat mixed reviews.

- Several studies have found that patients want therapists to be have a solid working knowledge of EDs and think that there should be more specialists in the field (Beresin et al., 1989; Newton, Robinson, & Harley, 1993).

It also appears in some studies that therapists need to be knowledgeable about EDs in order to truly convey empathy and make patients feel understood.



- On the other hand, two studies uncovered ambiguous results. One study found that while patients who viewed their therapist as *experts on EDs* were more satisfied with treatment, only 35% of participants rated *knowledge of EDs* as important (Rosenvinge & Klusmeier, 2000). Another study found that therapists' specific knowledge of EDs was not judged as a matter of vital importance (Pettersen & Rosenvinge, 2002).

10 Treatment Elements

#8 Behavioral Interventions

Behavioral interventions have a long history in the treatment of EDs. The research on patients' perspectives on behavioral interventions has yielded mixed results.

- One study of women who received CBT found that more than half the participants felt that specific behavioral strategies, such as diary keeping and practicing the use of distracting behaviors, were helpful (Le Grange & Gelman, 1998).
- Half of the participants in this study also reported that some behavioral strategies were unhelpful. They experienced the demand to monitor food intake when symptoms were too powerful as troublesome, and they complained about the prescriptive nature of treatment.
- Another study of women who received treatment for AN, found that participants who relapsed felt dissatisfied with treatment because behavioral goals (e.g., weight restoration) overshadowed the identification and processing of core psychological issues (Federici & Kaplan, 2008).

Much of the literature describes that interventions which focus exclusively on weight are viewed negatively by patients and there is a need to address wider issues than food and weight in treatment (Bell, 2003).



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10 Treatment Elements

#9 Appropriate Use of Medication

Medications have been widely utilized and advocated for EDs (Garfinkel & Walsh, 1997). Research has found that antidepressants are effective as one component of treatment for BN and BED patients (APA, 2006). SSRIs in combination with psychotherapy are also often used in treating patients with AN (APA, 2006). A few studies have inquired about patients' views on using medication in ED treatment.

- Several studies have found that patients with EDs find drug therapy helpful to some degree. One study found that medication was seen as a buffer to strong emotions, a help to overcome a crisis, and a regulator of food and hunger (Pettersen & Rosenvinge, 2002).
- Other studies have uncovered mixed views of medication. One study of ED patients found that 50% of patients felt that medication was helpful and 50% felt that medication was unhelpful (Newton et al., 1993).
- A final study of AN patients found that while none of the participants felt that medication was helpful for symptoms of AN, it was viewed as helpful for anxiety, depression, and insomnia (Beresin et al, 1989).



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10 Treatment Elements

#10 Therapist's Competence in Family Dynamics

Two studies have uncovered patients' views of family dynamics in relation to their ED.

- One study of women who recovered from AN found that the most frequently mentioned causal factor of the ED was a dysfunctional family (Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003). The authors of this study reported that while there is no evidence of a *typical* AN family, specific patterns of family interaction have been observed (e.g., rigidity, overprotectiveness, excessive control, and marital discord).
- It has also been reported that patients with BN “view their families as conflicted, badly organized, uncohesive, and lacking in nurturance or caring” (Vandereycken, 2002b, p. 216).
- On the other hand, Beresin et al. (1989), in their study of 13 women who recovered from AN, found that patients emphatically stated that:

A serious error in psychotherapy is to
blame parents excessively.



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Research Studies on Patients' Perspectives

This is a chronological table of all of the studies that have been conducted on patients' perspectives on treatment. This table provides information on which areas of treatment each study investigated.

Year of Publication and First Author	Overall Treatment Satisfaction	Treatment Modalities	Therapeutic Relationship	Provision of Social Support	Collaborative Treatment	Focus on Emotions	Focus on Underlying Issues	Inclusion of Psychoeducation	T. Knowledge of EDs	T. Competence in Family Dynamics	Behavioral Interventions	Use of Medication
1985: Maine	X	X	X	X		X					X	
1989: Beresin		X	X	X		X			X	X		X
1989: Yager	X											
1991: Lemberg		X										
1993: Newton									X		X	X
1993: Newton (2)		X									X	X
1993: Rorty			X	X			X	X			X	X
1998: Le Grange	X		X			X		X			X	
1998: Noordenbos	X										X	
2000: Rosenvinge	X	X	X	X					X			
2001: Button	X	X	X		X						X	X

Table continues on next page

Research Studies on Patients' Perspectives

Year of Publication and First Author	Overall Treatment Satisfaction	Treatment Modalities	Therapeutic Relationship	Provision of Social Support	Collaborative Treatment	Focus on Emotions	Focus on Underlying Issues	Inclusion of Psychoeducation	T. Knowledge of EDs	T. Competence in Family Dynamics	Behavioral Interventions	Use of Medication
2001: Swain-Campbell	X	X	X							X		
2002: Pettersen			X	X			X					X
2003: Tozzi				X						X		X
2004: Clinton	X				X							
2004: Krautter		X										
2005: Weaver	X											
2006: De la Rie	X		X	X	X		X		X			X
2006: Paulson-Karlsson	X	X			X				X			
2007: Vanderlinden			X	X			X					
2008: De La Rie			X		X		X					
2008: Federici			X	X		X	X	X			X	

Limitations of the Research Literature

While research on patients' perspectives on ED treatment has expanded in recent decades, there is a need for additional studies in this field. Considering the studies that have been conducted to date, a number of limitations of this literature need to be considered.

- For this project a total of 22 studies on a patients' perspectives on ED treatment were located. There is need for more studies in this field in order to enhance the generalizability of the findings.
- Many of the studies in this field have been conducted with AN patients. There is a need for more studies with BN and ED-NOS patients.
- These studies have included a limited number of male participants.
- A limited number of the studies in this field have been conducted in the United States.
- Many of these studies do not include information on the ethnicity of the participants.



Recommendations for Practitioners

This booklet is designed to be a thought-provoking resource that encourages practitioners to think beyond their customary explanations and treatment approaches. Practitioners should also be mindful of the need to create individualized treatment plans for patients with EDs. The research on patients' perspectives on ED treatment has discovered that what works for one patient may not work for another. Listed below are some recommendations for utilizing this resource to create successful treatments.

- Pay careful attention to where your patient fits in terms of diagnosis.
- Remember to explore etiological issues with your client. Understanding the development of one's ED offers unique insights into the path to recovery.
- Carefully read the information provided on the 10 treatment elements and consider how each element might apply to your particular patient.
- Be sure to focus on the therapeutic relationship throughout treatment. Create an understanding, supportive, and non-judgmental environment for you patient.
- Remember the importance of social support throughout the treatment process.
- Ask your patient for feedback on the way you are working together. Inquire about if you are focusing correctly.
- Be flexible in your work and create a treatment plan that matches the specific needs of your patient.
- Remember to evaluate and modulate treatment plans on a regular basis.

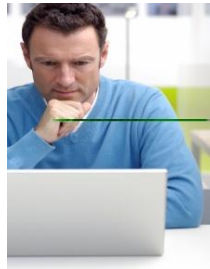
Part III: Additional Resources

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Eating Disorder Organizations

The following list of organizations is provided to give readers additional sources of information on EDs. These organizations offer information about the nature and treatment of EDs, as well as advocacy and prevention information.

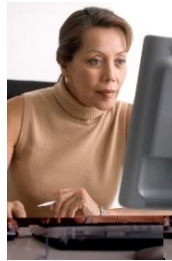
- Academy for Eating Disorders (AED)
www.aedweb.org
AED is a professional organization which holds an annual international conference and publishes a bi-monthly journal, the *International Journal of Eating Disorders*.
- Eating Disorders Coalition for Research, Policy, and Action (EDC)
www.eatingdisorderscoalition.org
EDC is an organization committed to advancing the federal recognition of EDs as a public health priority.
- International Association of Eating Disorder Professionals (IAEDP)
IAEDP is a professional organization offering a certification process for those who want to receive specialized credentials in working with people with EDs. IAEDP also publishes a newsletter which addressed contemporary treatment issues.
- National Eating Disorders Association (NEDA)
www.nationaleatingdisorders.org
NEDA is a non-profit organization devoted to providing education, resources, and support to those affected by an ED. NEDA holds an annual conference and their website includes helpful information on EDs.



Helpful Websites

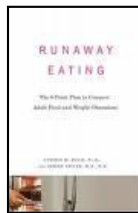
The following list includes websites that readers may find helpful. These sites are excellent resources for ED referrals, publications, and helping patients create a support group.

- BodyPositive
www.bodypositive.com
A great source of information, including links to other resources, to promote positive body image in people of all ages.
- Eating Disorder Referral and Information Center
www.edreferral.com
This site includes the most comprehensive search database of ED professionals around the world. Whether you are looking for a private practice professional or an inpatient hospital, this site should meet your needs.
- Gürze Books
www.gurze.com
Gürze Books is a publishing company that specializes in ED publications and education. On their website, you can find many great books, DVDs, and newsletters on EDs, body image, and obesity.
- Something Fishy
www.somethingfishy.org
A site dedicated to raising awareness and providing support to people with EDs and their loved ones. An excellent resource for topics such as prevention, online support, medical issues, and finding help.

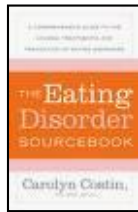


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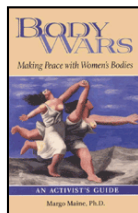
Books for Professionals and Patients



Bulik, C. M., & Taylor, M. (2005). *Runaway eating: The 8-point plan to conquer adult food and weight obsessions*. Emmaus, PA: Rodale.
A self-help oriented book geared toward women in midlife with eating and body image difficulties.

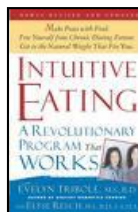


Costin, C. (2007). *The eating disorder sourcebook: A comprehensive guide to the causes, treatments, and prevention of eating disorders* (3rd ed.). New York, NY: McGraw-Hill.
An excellent resource for ED sufferers, loved ones, and professionals. Written in an easy to read fashion by a specialist who has been in the field for 30 years.



Maine, M. (2000). *Body wars: Making peace with women's bodies*. Carlsbad, CA: Gurze Books.

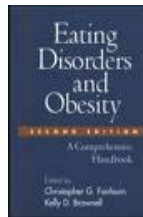
An inspirational activist's guide for patients, therapists, parents, and educators. Covers a wide range of topics, including: respecting women's bodies, obesity, dieting, the pursuit of beauty, media influences, and male issues.



Tribole, E., & Resch, E. (2003). *Intuitive eating: A revolutionary program that works* (2nd ed.). New York, NY: St. Martin's Press.

An excellent book on the downfalls of dieting written by nutritional therapists. Presents the intuitive eating philosophy which focuses on nurturing your body and freeing yourself from the diet mentality.

Books for Professionals



Fairburn, C. G., & Brownell, K. D. (Eds.). (2002). *Eating disorders and obesity* (2nd ed.). New York, NY: The Guilford Press.

Contains over 100 articles from experts in the field on topics such as etiology, epidemiology, sociocultural issues, treatment, prevention and medical aspects.



Garner, D. M., & Garfinkel, P. E. (Eds.). (1997). *Handbook of treatment for eating disorders* (2nd ed.). New York, NY: The Guilford Press.

Contains a wealth of information from experts in the field on topics such as the history of EDs, treatment approaches, hospital and drug treatments, and special interest areas (e.g., sexual abuse).



Maine, M., Davis, W. N., & Shure, J. (Eds.). (2009). *Effective clinical practice in the treatment of eating disorders: The heart of the matter*. New York, NY: Routledge.

An excellent reference for both novice and seasoned therapists which addresses topics beyond theoretical approaches and behavioral strategies.



Thompson, J. K., & Cafri, G. (Eds.). (2007). *The muscular ideal: Psychological, social, and medical perspectives*. Washington, DC: American Psychological Association.

Draws on new research to provide an overview of the muscular ideal. Chapters also cover related issues, such as steroid use, repeated cosmetic surgery, and prevention issues.

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Chapter V: Discussion

Overview

EDs are life-threatening illnesses that are difficult to treat even under the best of circumstances. The purpose of this dissertation was to create a resource for clinicians to help in their treatment of patients with EDs. In recent years, there has been an increase of studies on patients' perspectives on ED treatment, illuminating the helpful nature of various treatment elements. Understanding the patient's view is a vital component of creating effective treatments. Patient satisfaction plays a key role in the therapeutic relationship and treatment outcome. Patients offer the unique insight of what it is like to suffer from an ED and undergo ED treatment. Recovered patients, in particular, are able to provide practitioners with an understanding of the treatment factors that helped them overcome their illness. Despite the importance of understanding the patient's perspective, most of our knowledge in the field of EDs comes from the outside perspective of researchers and clinicians who view recovery as behavioral responses (Weaver et al., 2005). There is a great need to increase our understanding of the patient's view of treatment.

The procedure for this dissertation was to synthesize all of the literature to date on patients' perspectives on ED treatment in order to make this information more accessible to clinicians. An extensive and comprehensive literature review of EDs was conducted for this project. The author identified a total of 22 articles on patients' perspectives on ED treatment. Experts in the field of patients' perspectives on ED treatment were also contacted in order to inquire about any additional articles. A total of four experts were contacted and three of them responded. The fourth expert did not respond; however, her

co-author was one of the other experts who did respond. Through contact with these experts, it was determined that the author had all of the available articles for this project.

Based on the literature review, a 61-page resource booklet was created. Initially, a 30-35 page booklet was proposed; however, during the development stage it became clear that the booklet needed to be lengthened. It was necessary to make the font larger than initially planned and to include a variety of pictures in order to enhance the readability of the booklet. In addition, more background information about EDs was included. The resource covers a broad range of topics: history, statistics, etiology, cultural diversity, treatment options, and patients' perspectives on treatment. The booklet also provides additional resources for practitioners, such as ED organizations, helpful websites, and books on EDs. This booklet is intended to guide practitioners in adapting their treatments to meet the needs of their patients. The researchers of patients' perspectives emphasize the importance of creating individualized treatments for patients with EDs. The studies in this area have found that patients have varying opinions about some treatment elements, such as behavioral interventions and medications. It is important that clinicians be flexible in creating treatments that match the individual needs of each client. This resource was designed to be thought-provoking and to encourage practitioners to be mindful of their patients' satisfaction with treatment.

Strengths of the Resource

This resource is the only one that synthesizes the literature on patients' perspectives on ED treatment for practitioners. It will help clinicians create individualized treatment plans for patients with EDs by providing an increased understanding of the varied experiences that patients have in treatment.

This resource provides practitioners with information on a wide-range of topics in an easy-to-read manner. A detailed table of contents is provided at the beginning of the resource so that practitioners can easily locate topics that are of interest to them. The resource also includes a table with all of the studies on patients' perspectives on EDs and all of the treatment elements, illustrating which studies presented data on specific treatment elements. Information on each of the treatment areas is presented in a concise, reader-friendly manner. The resource also contains additional resources for practitioners, such as ED organizations and books, to guide them in learning more about EDs. The resource includes pictures, diagrams, charts, and highlighted key points in order to gain the reader's attention. Finally, a reference list is provided so that practitioners can locate literature that is of interest to them.

Limitations of the Resource

There are several limitations of this resource. First, the resource is only as strong as the literature on patients' perspectives on ED treatment. There are several limitations of this literature, which were described in Chapter II and in the resource. There is a limited amount of research that has been conducted on patients' perspectives on ED treatment, with only a few studies having been conducted in the United States. Moreover, many of the studies on patients' perspectives have included AN patients and there is less information available on the views of patients with BN and ED-NOS. The male perspective is also underrepresented in this literature. Finally, although studies on patients' perspectives have been conducted in numerous countries around the world, many of these articles provided limited or nonexistent information on the ethnicity of the participants.

A second limitation of this resource is that it was designed for therapists who work with ED patients on an outpatient basis and is not designed for work in inpatient or residential settings. Practitioners who work in inpatient settings need to attend to a host of medical concerns. EDs are deadly and AN has the highest mortality rate of all psychiatric illnesses. A resource for therapists who work in inpatient settings should address the specific needs of patients in these settings. Nevertheless, while this resource is geared for work with outpatient populations, practitioners in inpatient settings may find the information in the resource helpful in directing them to the research that has been conducted on patients' perspectives on treatment.

Third, this resource is not meant to be a comprehensive guide on ED treatment. While current treatment options are reviewed in the resource, the information provided is not sufficient for gaining a solid understanding of effective ED treatment. This resource covers one portion of creating effective ED treatments: the patients' perspective.

Therapists who want to gain a complete understanding of ED treatment and studies that have been conducted in this field should consult The American Psychiatric Association's *Practice Guidelines for the Treatment of Patients with Eating Disorders, Third Edition* (2006) or books that provide comprehensive information on treatment, such as *Effective Clinical Practice in the Treatment of Eating Disorders: The Heart of the Matter* (2009).

Last, while this resource was developed with the goal of helping practitioners in their treatment of patients with EDs, it has not undergone empirical testing. The usefulness of this resource is only assumed, based on the value of understanding the patient's perspective of treatment, and informal feedback from peers and faculty members. To assess the usefulness of this resource, a formal evaluation would need to be

undertaken. A possible future plan for evaluating this resource is described in the subsequent section.

Plans for Future Evaluation, Revision, and Dissemination

An important next step in the development of this resource would be to have it formally evaluated by practitioners. The evaluation process should begin with the distribution of the resource to practitioners who work in outpatient settings with ED patients, such as private practice offices or university counseling centers. The author would ask the practitioners to review and critique the manual via a questionnaire or an interview. Another option would be to conduct a focus group with practitioners who have reviewed the resource. During the evaluation process, participants would be asked to provide feedback about the format and content of the manual, with particular attention placed on the evaluation of the information on patients' perspectives on ED treatment. Participants could also be asked to comment on the appearance, style, and readability of the resource. Once the evaluation of the resource was complete, it would be important to revise the resource based on the feedback provided.

Dissemination of this resource is premature at this time, as it is in draft form and has not yet been evaluated. Distribution of the resource would only occur after it has been evaluated and then modified. Once the resource has been completed and is found to be helpful, there are a variety of options for distributing it. The author could send an email to members of psychotherapy organizations or ED organizations, such as Division 29 of the American Psychological Association, the Los Angeles County Psychological Association (LACPA) or the Academy for Eating Disorders (AED), and announce the availability of the resource. The author could attend meetings for special interest groups, such as the

Women's Issues special interest group of LACPA, and bring copies of the resource. The author could contact university counseling centers and ask if staff members are interested in a copy of the resource. Finally, the author could attend ED conventions, such as the annual AED convention, and pass out a one-page flier about the resource, its contents, and how to contact the author for a copy.

EDs are a worldwide problem and many of the studies on patients' perspectives have been conducted in countries outside the United States. If the resource received positive evaluations once disseminated in the United States, another option would be to have the resource translated into other languages in order to share it with a wider group of practitioners.

Conclusion

The patient's perspective is rarely considered when psychological treatments are evaluated. After a review of the literature and the creation of the resource, the author identified areas for future research on patients' perspectives. First, there is a great need for studies on patients' perspectives on EDs to include more diverse populations. Studies should include more male participants, more participants with ED-NOS and BN, and more ethnicity diverse participants. Second, there is a need for studies to delve more deeply into patients' perspectives on the treatment elements. For instance, patients' have expressed that learning to manage emotions and working through underlying issues are important in treatment. Future research should inquire about the different ways in which therapists address these topics and how patients' feel about the quality of these interventions. In this regard, there is a need for additional qualitative studies which offer the unique opportunity of gaining in-depth feedback from patients.

It is hoped that this resource will prove to be a useful tool for practitioners, especially those who work in relative isolation from their colleagues with expertise in EDs, such as private practice psychotherapists. The literature on patients' perspectives on ED treatment is not easy to access and the intent of this project was to create a resource that brings this information closer to those who can utilize it. In conclusion, the results of this project indicate that there is a great deal to be learned from ED patients about their illness and their journey to recovery.

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- Yager, J., Landsverk, J., & Edelstein, C. K. (1989). Help seeking and satisfaction with care in 641 women with eating disorders. *The Journal of Nervous and Mental Disease, 177*, 632-637.

APPENDIX A

Literature on Patients' Perspectives on Eating Disorder Treatment

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
Bell, L. (2003). What can we learn from consumer studies and qualitative research in the treatment of eating disorders? <i>Eating and Weight Disorders</i> , 8, 181-187.	None	Literature review of 23 studies that involved qualitative research and/or questionnaire surveys with ED patients	<ol style="list-style-type: none"> 1. Supportive and empathic relationships are critical to recovery and treatment. 2. Supportive relationships with people outside therapy significantly impact treatment. 3. Individual therapy and group therapy are consistently reported as the most helpful. 4. Many patients report that medication is unhelpful. 5. Interventions which focus exclusively on weight are reported negatively and many studies identify the importance of addressing wider issues. 6. Patients benefit from having some control over the process and pace of treatment. 	<ol style="list-style-type: none"> 1. There are major gaps in consumer research in the field of EDs. 2. Many studies in the field have significant methodological weaknesses. 3. Focus groups have yet to be utilized with the ED population. 4. Treatment can be not only ineffective but experienced as negative. 	Does not provide details on the studies that were reviewed.
Beresin, E. V., Gordon, C., & Herzog, D. B. (1989). The process of recovering from anorexia nervosa. <i>Journal of American Academy of Psychoanalysis</i> , 17, 103-130.	13 women who recovered from AN and responded to ads placed in a newsletter of an organization devoted to helping ED patients	90 minute semi-structured interview and questionnaires	<ol style="list-style-type: none"> 1. Individual psychotherapy was by far the highest rated of all treatment and also viewed as potentially the most destructive. 2. It is very important in therapy for both the therapist and patient to tolerate feelings. 3. Therapists must have a solid working knowledge of EDs. 4. Medications were not found to be helpful in alleviating AN symptoms but were useful for anxiety and depression. 	<ol style="list-style-type: none"> 1. A person suffering from AN has no idea what it is like to be a real person with a cohesive sense of self, known and loved by others for herself. The process of recovering from AN is the process of becoming a person. 2. The essential therapeutic agent is the establishment of a relationship. 	<ol style="list-style-type: none"> 1. Small sample size 2. Only AN participants 3. Only female participants 3. Possible sampling bias if the non-respondents have different views from those who responded. 4. Possible interview bias in that the semi-structured interview allowed for variation among interviewers.

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
Button, E. J., & Warren, R. L. (2001). Living with anorexia nervosa: The experience of a cohort of sufferers from anorexia nervosa 7.5 years after initial presentation to a specialized eating disorders service. <i>European Eating Disorders Review</i> , 9, 74-96.	36 patients who received treatment for AN 7.5 years prior at an ED service site in the United Kingdom	Semi-structured interview and a series of questionnaires	<ol style="list-style-type: none"> 1. A wide range of experiences in treatment were reported. Some participants found treatment helpful and others found it unhelpful. 2. Two areas were identified as unhelpful or harmful: attitudes of staff and overemphasis on weight. 3. There was considerable consensus regarding the importance of individual psychotherapy/counseling and the quality of the therapeutic relationship. 4. Many participants expressed that a range of help was required and this included family and friends. 	<ol style="list-style-type: none"> 1. This study highlighted the differing requirements and treatment expectations of sufferers. Treatment providers need to be prepared to tailor services to consumer's individual needs. 2. Treatment needs to extend well beyond weight restoration. 3. Future research needs to pay greater attention to the long-term needs of AN patients. 	<ol style="list-style-type: none"> 1. Only AN participants 2. Relatively low response rate from patients (i.e., 46%)
Clinton, D., Björck, C., Sohlberg, S., & Norring, C. (2004). Patient satisfaction with treatment in eating disorders: Cause for complacency or concern? <i>European</i>	469 former patients (462 females, 7 males) who received treatment 36 months prior in Sweden. Diagnoses included AN, BN, BED, and ED-NOS	A questionnaire focused on initial reception at the treatment unit, suitability of treatment, ability of staff to listen and understand, confidence in the unit and agreement on treatment goals	<ol style="list-style-type: none"> 1. After 36 months, 38% of patients were <i>highly satisfied</i> with treatment, 39% were <i>satisfied</i>, and 23% were <i>unsatisfied</i>. 2. Satisfaction was predicted by treatment interventions focusing on support and increased control of eating problems. 3. Unsatisfied patients had previously been less prepared 	<ol style="list-style-type: none"> 1. We may be less successful with patients who have a greater number of interpersonal problems and who are not focused on their symptoms of disordered eating. 2. Practitioners who utilize individual and group CBT and psychoeducative programs may be encouraged by patient satisfaction with 	The questionnaire used only five questions and a three point scale to measure treatment satisfaction.

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
<i>Eating Disorders Review, 12, 240-246.</i>			to change their eating habits, had higher levels of conflict with their fathers, had a lesser degree of present weight acceptance and tended to expect less from treatment interventions focusing on control of eating problems.	treatment strategies that focus on control over eating habits and support. 3. It is essential for therapists to listen more carefully to their patients and consider their expectations when planning and providing treatment.	
De la Rie, S., Noordenbos, G., Donker, M., & van Furth, E. (2006). Evaluating the treatment of eating disorders from the patient's perspective. <i>International Journal of Eating Disorders, 39, 667-676.</i>	41 AN patients, 43 BN patients, 69 ED-NOS patients, and 148 former ED patients recruited from the community in the Netherlands	Multiple questionnaires, including, Questionnaire for Eating Problems and Treatment, which addressed treatment history and the patient's evaluation of their treatment.	1. Treatment in specialized ED centers, self-help groups, and involvement of a partner in treatment were seen as the most helpful. 2. Helpful components of nonspecialized treatment were: good working alliance, being able to tell their story, feeling understood, feeling supported, and gaining insight into one's problems. 3. Negative aspects of nonspecialized treatment were: lack of understanding or empathy due, in part, to a lack of knowledge of EDs, lack of focus of treatment on ED pathology, and lack of support. 4. Support from other ED patients was mentioned as valuable.	1. The extent to which treatment goals are negotiated may explain differences in satisfaction with interventions. 2. ED patients appreciate a collaborative approach with a therapist who has good communication skills. 3. The illness perception of ED patients may affect the evaluation of treatment.	1. The advertisement to participate in the study may have appealed to those who have a history of different ED treatments. 2. The participant group may have had more severe ED pathology than did a randomly selected sample.
De la Rie, S., Noordenbos, G.,	156 current ED patients and 148	The Questionnaire for	1. Both therapists and patients most often mentioned	1. To a therapist, a <i>progressing</i> patient will be	1. Therapists were recruited from specialized ED centers and

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
Donker, M., & van Furth, E. (2008). The quality of treatment of eating disorders: A comparison of the therapists' and the patients' perspective. <i>International Journal of Eating Disorders, 41</i> , 307-317.	former ED patients recruited from the community in the Netherlands. 73 therapists working with ED patients recruited from specialized treatment centers	Eating Problems and Treatment	treatment focus, therapeutic alliance, and communication skills as important aspects of treatment; however, they valued similar topics differently. 2. Therapists most often stressed the focus on ED symptoms and behavioral change, whereas patients stressed the importance of the therapeutic relationship and the need to address problems underlying the ED.	willing to work on behavioral change, whereas to a patient, a <i>helpful</i> therapist will be understanding and willing to focus on the patient as a person and not merely on behavioral symptoms. 2. ED patients may stress the importance of a good therapeutic alliance because they find it particularly challenging to engage in a relationship with the therapist. This difficulty may be related to attachment style and early life experiences.	were, therefore, more experienced with EDs than a randomly selected group of therapists. 2. The advertisement to participate in the study may have appealed to those who have a history of different ED treatments. 3. The participant group may have had more severe ED pathology than did a randomly selected sample.
Federici, A., & Kaplan, A. S. (2008). The patient's account of relapse and recovery in anorexia nervosa: A qualitative study. <i>European Eating Disorders Review, 16</i> , 1-10.	15 patients who had successfully completed intensive treatment at Toronto General Hospital	Qualitative semi-structured interviews	1. Women in the weight-recovered group were consistently more satisfied with their treatment than those who relapsed. 2. Weight-recovered participants stated that they felt safe, supported, and validated throughout treatment and that specific interventions (e.g., psychoeducation) had been essential components of their recovery). 3. The participants who relapsed reported	1. There is a great deal to be learned from ED patients about their illness. 2. Qualitative and in-depth approaches provide a rich understanding into the process of recovery. 3. AN patients have various and unique treatment needs and some patients may require different or additional treatment post-weight restoration.	1. Small sample size 2. Only AN participants 3. All the participants were women, Caucasian, middle to upper class, and well-educated. 4. The findings were based on the personal stories participants selectively chose to disclose.

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			dissatisfaction with their treatment. They felt that behavioral goals of treatment (e.g., weight restoration) overshadowed the identification and processing of core psychological and emotional issues. 4. Participants who relapsed also reported that follow-up care had been too rigid and behavioral in orientation. They felt that too little attention had been given to issues involving relationships, stressors, and negative emotions.		
Krautter, T., & Lock, J. (2004). Is manualized family-based treatment for adolescent anorexia nervosa acceptable to patients? Patient satisfaction at the end of treatment. <i>Journal of Family Therapy</i> , 26, 66-82.	Members of 34 families, including 35 mothers, 31 fathers and 32 adolescents. All participants completed family-based treatment for AN in the United States	Qualitative and quantitative questionnaires	1. The adolescent patients found all of the treatment components to be in the effective range. 2. A quarter of participants suggested that individual therapy, more family therapy, and focusing on other issues besides AN would improve treatment.	The data suggest that a manual-driven family-based treatment for adolescents with AN is acceptable to patients though including additional therapy, individual therapy in particular, might be considered.	1. Only AN participants 2. Sample was relatively small 3. The opinions of those who dropped out of treatment (i.e., 12%) are not represented. 4. Participant had a high socioeconomic status.

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
Le Grange, D., & Gelman, T. (1998). Patients' perspective of treatment in eating disorders: A preliminary study. <i>South African Journal of Psychology</i> , 28, 182-186.	21 females who received treatment at an outpatient university-based ED service in South Africa	Semi-structured qualitative interview	<ol style="list-style-type: none"> 1. Most patients reported improvements as a result of the treatment. 2. The participants identified psychoeducation, a supportive environment, challenging dysfunctional beliefs, and behavioral strategies as helpful components. 3. Participants reported that some behavioral strategies were unhelpful, including: food monitoring when they were overwhelmed and the prescriptive nature of treatment. 4. Six patients expressed that treatment was inadequate in addressing the causes of the ED. 5. Four patients felt that personal problems were not dealt with sufficiently. 	<ol style="list-style-type: none"> 1. The results of this study should caution practitioners that some interventions may exacerbate feelings of inadequacy. 2. Patients with more severe illnesses felt discouraged by behavioral strategies. Treatment providers need to better address the needs of severely ill patients. 	<ol style="list-style-type: none"> 1. Small sample size 2. Only female participants 3. A standardized interview was not utilized, which may have allowed for interview bias.
Lemberg, R., & May, M. (1991). What works in in-patient treatment of eating disorders: The patient's point of view. <i>British Review of Bulimia and</i>	28 patients suffering from AN or BN who completed a treatment program (25 female, 1 male, and 2 unspecified)	52-item forced choice questionnaire and opportunity to write in personal comments	<ol style="list-style-type: none"> 1. Patients identified exercise group, one-to-one with psychiatrist/psychologist, nutrition group, ED group and one-to-one with primary nurse as the most helpful therapies. 2. Patients found family education, occupational therapy, biogenics, evening lecture, art therapy, and agenda 	<ol style="list-style-type: none"> 1. Some of the therapies cited as <i>most helpful</i> by some patients were cited as <i>least helpful</i> by others. There is a need to address the varying issues of the entire patient population. 2. Measuring patient satisfaction can be useful in eliminating unhelpful 	<ol style="list-style-type: none"> 1. Response rate was 50%. It is possible that the most dissatisfied patients did not respond to the survey. 2. All participants received treatment at the same inpatient facility.

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
<i>Anorexia Nervosa</i> , 5, 29-37.			group as least helpful. 3. Staff were seen as lacking in consistency and in clarity (e.g., one patient reported being confused by each therapist approaching her with a different outlook on her problems).	therapies.	
Maine, M. (1985). Effective treatment of anorexia nervosa: The recovered patient's view. <i>Transactional Analysis Journal</i> , 15, 48-54.	25 participants with a history of AN	An in-depth, semi-structured interview developed by the author in a separate pilot study	1. Five participants saw their treatment as essential to their recovery; 3 saw their treatment as harmful to their recovery; 16 rated their treatment as equivocal. 2. The participants who believed their treatment was essential to recovery described therapy as validating, affirming, and accepting.	1. Very little of formal treatment appeared essential to participants. 2. A relationship with a warm, nurturing, understanding person who provides empathy is essential.	1. Small sample size 2. A standardized interview was not utilized, which may have allowed for interview bias.
Newton, T. (2001). Consumer involvement in the appraisal of treatments for people with eating disorders: A neglected area of research? <i>European Eating</i>	None	Review of literature	1. Future research should identify standardized approaches to the measurement of treatment perceptions. 2. It would be interesting to note the variables which influence perceptions of treatment (e.g., outcome and severity of illness).	1. Consumer involvement raises several theoretical and methodological issues. 2. There is a need for fundamental research devising methods for determining the perceived quality of treatment amongst people with EDs.	

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
<i>Disorders Review, 9, 301-308.</i>					
Newton, T., Hartley, P., & Sturme, P. (1993). Treatment evaluation for eating disorders by clients with eating disorders. <i>Behavioural and Cognitive Psychotherapy, 21, 371-374.</i>	54 participants with EDs who attended a college-based, group counseling service	Participants read a vignette and then completed the Treatment Evaluation Inventory (a standardized, widely used measure of treatment acceptability)	<ol style="list-style-type: none"> 1. <i>Discussion of problems</i> was rated most favorably. 2. Drug treatment was rated significantly less favorably than the other 3 treatments. 	Future research should examine the evaluation of treatments across different clinical populations and at different stages of treatment.	<ol style="list-style-type: none"> 1. All participants received the same form of treatment before the study. 2. Only 1 male participant.
Newton, T., Robinson, P., & Hartley, P. (1993). Treatment for eating disorders in the United Kingdom. Part II. Experiences of treatment: A survey of members of the eating disorders association. <i>Eating Disorders Review, 1, 10-</i>	1638 females and males who received treatment for an ED in the United Kingdom	Postal questionnaire	<ol style="list-style-type: none"> 1. Of the participants who underwent behavior therapy, 69% felt that it was unhelpful or made their situation worse. 2. Areas identified by respondents as needing improvement included: more opportunity to talk about your illness with someone who understands the difficulties, more counselors trained to deal with EDs, more specialists in EDs, better outpatient and inpatient treatment for EDs, more support for families with EDs, and more self-help groups. 	<ol style="list-style-type: none"> 1. Sufferers may be more willing to accept treatment if the services are perceived as more helpful and relevant. 2. The results indicate that service providers should seek consumers' feedback and rectify the poor state of service provision for EDs in many parts of the United Kingdom. 	<ol style="list-style-type: none"> 1. Sample included only 39 males. 2. Patients with AN were overrepresented in the sample.

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21.			3. Counseling and self-help groups were regarded by a large majority as helpful.		
Noordenbos, G., Jacobs, M. E., & Hertzberger, E. (1998). Chronic eating disorders: The patients' view of their treatment history. <i>Eating Disorders</i> , 6, 217-223.	98 chronic patients (i.e., those suffering from an ED for 10 years or more)	Analyzed letters written by the patients to the Dutch Foundation of Anorexia and Bulimia Nervosa	1. Chronic patients were often afraid of treatment because of negative experiences. 2. Patients who had received tube feeding or behavior therapy were usually negative about these treatments. During or after these treatments they often became depressed, sometimes suicidal.	1. The treatment of chronic patients with EDs leaves much to be desired. 2. When patients have had negative treatment experiences, it might be advisable to help them learn to talk about their frustrations before trying to get them motivated about a new kind of therapy.	The researchers do not provide details on their methodology, which precludes a critical evaluation.
Paulson-Karlsson, G., Nevenon, L., & Engström, I. (2006). Anorexia nervosa: Treatment satisfaction. <i>Journal of Family Therapy</i> , 28, 293-306.	32 female ED patients and 41 parents who had participated in a mean of 17 family sessions at a hospital in Sweden; 25 patients also received individual sessions; 22 families had parental sessions	The Treatment Satisfaction Scale (self-report questionnaire)	1. Seventy-three percent of patients and 83% of parents felt that their treatment expectations had been fulfilled. 2. Ten patients who initially did not want any help thought that they had been helped after all. 3. The majority agreed that individual patient sessions and parental sessions were of great help, while the patients valued family therapy sessions as being less helpful than did parents. 4. The majority of patients and parents had a positive experience of the therapist,	1. In order to understand treatment resistance in AN patients, it is important to investigate patients' expectations and experiences of treatment. 2. Overall, parents were more pleased with the therapists than were the patients. 3. Family-based treatment including individual sessions for patients and parental sessions corresponds well to patients' and parents' treatment expectations.	1. Relatively small homogenous sample 2. Only AN participants 3. The questionnaire was not anonymous and, therefore, participants may have been reluctant to give some feedback.

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			including: therapist capable of helping; therapists' knowledge and understanding of EDs; were listened to; agreed on the content of treatment; participated in treatment planning; encouraged to talk about important issues; and met in a kind way.		
Pettersen, G., & Rosenvinge, J. H. (2002). Improvement and recovery from eating disorders: A patient perspective. <i>Eating Disorders, 10</i> , 61-71.	Forty-eight women, 18 years or older who had an ED for at least 3 years and had received professional treatment. Participants were recruited from patient organizations and a university ED unit in Norway.	Standardized questionnaires and qualitative interview	<ol style="list-style-type: none"> 1. <i>A wish to change</i> was an important recovery factor. 2. Judging therapy as effective was strongly associated with a therapeutic relationship which emphasized: support, empathy, respect, understanding, and seeing the individual "behind the symptoms." Good therapists were engaged, had time to listen, and were available. 3. Specific knowledge about EDs on behalf of the therapists was not judged as a matter of vital importance. 4. Meeting with other sufferers was judged to be helpful (i.e., this promoted a feeling of being able to recognize oneself in another). 5. Many participants valued a distance from parents as more helpful in order to recover. 	<ol style="list-style-type: none"> 1. When ED recovery is defined by clinicians, important aspects of the recovery process might be overlooked. 2. Specific knowledge about EDs on behalf of the therapists was not judged as a matter of vital importance. 	<ol style="list-style-type: none"> 1. Only female participants 2. Possible interview bias resulting from the use of an open-ended interview.

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			6. Other people in their lives (e.g., friends and partners) were seen as a main source of trust, acceptance, and practical and emotional support.		
Rorty, M., Yager, J., & Rossotto, E. (1993). Why and how do women recover from bulimia nervosa? The subjective appraisals of forty women recovered for a year or more. <i>International Journal of Eating Disorders, 14</i> , 249-260.	40 women who recovered from BN and were recruited by local advertisement and referral in the United States	Semi-structured interviews	<ol style="list-style-type: none"> 1. Women take divergent paths in the healing process; however certain distinct themes were apparent. 2. Parents were generally portrayed as unhelpful in recovery. 3. Most women viewed less obvious features as the most difficult to change (e.g., body image problems). 4. Most helpful treatment related experiences: empathy and understanding, contact with other bulimia sufferers, work on underlying issues, and education about EDs. 	<ol style="list-style-type: none"> 1. Women can and do recover from BN. 2. Recovered patients have much to offer to the treatment literature. 3. Humanistic qualities on behalf of the therapist were seen as the most helpful. 	<ol style="list-style-type: none"> 1. Only female participants 2. Only BN participants 3. Because the sample was recruited through advertisement, it may not have been representative of women in the community who have recovered from BN. 4. Possible interview bias in that the semi-structured interview allowed for variation among interviewers.
Rosenvinge, J. H., & Klusmeier, A. K. (2000). Treatment for eating disorders from a patient satisfaction perspective: a Norwegian	321 members of the Norwegian organizations for ED patients	68 item mailed questionnaire	<ol style="list-style-type: none"> 1. Participants were highly satisfied with outpatient individual and group therapy, and to a less extent with family therapy. 2. Participants who experienced therapists as competent on EDs reported higher treatment satisfaction. 3. <i>Understanding</i> was most 	One source of patient dissatisfaction may be therapist's negative view of <i>eating disorder families</i> , for instance as <i>overprotective</i> , <i>manipulative</i> , and <i>enmeshed</i> .	Response rate was not optimal to represent the opinion of members of the patient organizations (i.e., 54%).

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
replication of a British study. <i>European Eating Disorders Review</i> , 8, 293-300.			frequently identified as the helpful therapist quality. 4. Almost half of the participants reported family as contributing to improvement, while one third reported a contribution from friends.		
Swain-Campbell, N. R., Surgenor, L. J., & Snell, D. L. (2001). An analysis of consumer perspectives following contact with an eating-disorders service. <i>Australian and New Zealand Journal of Psychiatry</i> , 35, 99-103.	120 female patients with AN, BN, and ED-NOS who received treatment at a specialized ED service in New Zealand	Postal survey which included both a structured and an open-ended questionnaire format	1. Seventy-five percent of respondents endorsed assessment and treatment as either good or excellent. 2. The most frequently reported best feature of the service was components of the therapeutic alliance. 3. Respondents disliked the structure of treatment, including being weighed, and the perceived pressure to change. 4. Forty-three respondents provided comments regarding how services could be improved. Most comments requested changes in treatment modality or components (e.g., individual rather than group treatment, more support groups, and more lenient rules while on the weight gain program).	1. Consumer opinions form an important insight into the unique predicaments of people with EDs. 2. Staff need to be reminded of the potency of client perceptions of the working alliance as a source of satisfaction.	1. Only female participants 2. All participants received treatment at the same facility.
Tozzi, F., Sullivan, P. F.,	70 women who were referred	Extensive interviews	1. The most commonly mentioned factors related to	1. Little attention has been paid to the personal	1. Only female participants 2. All participants made contact

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
Fear, J. L., McKenzie, J., & Bulik, C. M. (2003). Causes and recovery in anorexia nervosa: The patient's perspective. <i>International Journal of Eating Disorders</i> , 33, 143-154.	for treatment of AN an average of 12 years earlier in New Zealand	including open ended questions	recovery were a supportive relationship or partner, maturation or growing out of the disorder, and therapy or counseling. 2. In many cases, becoming pregnant or desiring to start a family fueled the process of maturing out of the disorder. 3. Very few women reported that pharmacologic treatment played a significant role in recovery. 4. Individuals who had not recovered were more likely to have cited family weight and food issues and low self-esteem as causal factors of the disorder.	perspectives of ED patients. Patient perspectives, along with clinical data, can provide a valuable understanding of AN. 2. Relationships with either a partner or a therapist played a major role in recovery. Patients expressed that a supportive relationship was the driving force that assisted them in recovery.	with the same treatment facility. 3. Possible interview bias resulting from the open-ended questions.
Vanderlinden, J., Buis, H., Pieters, G., & Probst, M. (2007). Which elements in the treatment of eating disorders are necessary ingredients in the recovery process? A comparison between the	132 ED patients who received CBT therapy combined with a family therapeutic approach and 49 ED experts	Evaluation List for the Treatment of Eating Disorders - 20 items referring to the main therapeutic elements and tools utilized in the patient's treatment	1. <i>Improving self-esteem, improving body experience, and learning problems solving skills</i> were considered by patients to be core elements in their treatment. 2. No major differences were found between patients and therapists, inpatients and outpatients, or different diagnostic groups. 3. Patients stated that <i>support of therapist and learning to express one's opinions and</i>	If therapists and researchers listen carefully, they can learn a lot from their patients about what elements are needed in ED treatment.	1. The sample does not fully represent the ED population as participants had a relatively high age. 2. More than half the sample consisted of patients with BN. Patients with AN bingeing/purging-type were underrepresented. 3. The questionnaire mainly included questions of a cognitive-behavioral kind.

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
patient's and therapist's view. <i>European Eating Disorders Review</i> , 15, 357-365.			<i>feelings</i> were very important. 4. <i>Getting insight in their problems and underlying mechanisms</i> was highly appreciated by patients.		
Weaver, K., Wuest, J., & Ciliska, D. (2005). Understanding women's journey of recovery from anorexia nervosa. <i>Qualitative Health Research</i> , 15, 188-206.	12 women with varied AN and recovery experiences (age range: 14-63)	Feminist grounded theory	1. Constructed a theory of self-development from perilous self-soothing to informed self-care. 2. Recovery was depicted as self-awareness, self-differentiation, and self-regulation. 3. Majority of women perceived treatment as traumatic and defined recovery to some extent on their ability to <i>survive</i> treatment. 4. Women reported receiving the most help when others were open to their perspectives and concentrated on listening to and looking carefully at what was being revealed in the women's suffering.	1. Interventions must not focus on caring for the AN at the expense of ignoring the woman. 2. Majority of the women in this study perceived treatment as traumatic.	1. Only female participants 2. Small sample size
Yager, J., Landsverk, J., & Edelstein, C. (1989). Help seeking and satisfaction with	641 women with EDs who responded to an article in <i>Glamour Magazine</i>	A help-seeking and satisfaction questionnaire developed for this study	1. Thirty percent to 45% of respondents felt that their EDs were not sufficiently the focus of treatment. 2. Treatments were generally seen as helping <i>a little</i> .	1. Little has been reported about the experiences of ED patients. 2. EDs are chronic conditions that are difficult to treat under the best of circumstances.	1. Only female participants 2. Because of the self-report, nonclinical interview method, it is difficult to judge the validity of the data.

Reference Citation	Participants	Inquiry Strategy	Results Pertaining to the Present Project	Conclusions Pertaining to the Present Project	Limitations Pertaining to the Present Project
care in 641 women with eating disorders. <i>The Journal of Nervous and Mental Disease</i> , 177, 632-637.			3. Some respondents perceived Overeaters Anonymous and self-help groups as more harmful than helpful. 4. Participants whose treatments were with clinicians who were sought out because of their reputation with EDs reported that EDs were more often the focus of treatment, that they were open about their EDs during treatment, that they changed more, and that they perceived their treatments as more efficacious.	3. Despite reputations for working with ED patients some providers are not adequately skillful in the treatment of complicated ED cases.	

APPENDIX B

Example of Email Sent to Experts

Dear (Expert's Name):

My name is Danielle Davis and I am a clinical psychology doctoral student in the United States. For my dissertation, I am synthesizing all of the literature on patients' perspectives on eating disorder treatment. I am creating a resource booklet for practitioners that describes what we have learned from patients about what works for them in treatment and what does not. I am utilizing two of your articles for this project (i.e., your 2006 and 2008 articles in the *International Journal of Eating Disorders*).

Thank you for your contribution to our understanding of the patient's view of eating disorder treatment. I am writing to ask if you have any unpublished articles that I might include in my booklet. I have attached a chronological listing of the articles that I am using for my project. I would greatly appreciate it if you could scan this table to see if I might be missing any of the studies in this field. Also, if you have any general suggestions for my project, it would be wonderful to hear your ideas.

Thank you kindly,

Danielle Davis