Managing Severe and Enduring Anorexia Nervosa

Based on the only evidence-based randomized controlled trial yet undertaken in patients with severe and enduring anorexia nervosa, Managing Severe and Enduring Anorexia Nervosa uses the results of that trial to present a new paradigm for treatment. This informative new text assembles the leading scientists across several continents to provide a comprehensive overview and new paradigm for treatment and stimulate interest in the development of new psychosocial approaches. Students, clinicians, and researchers in the field of eating disorders will find this edited volume a valuable reference handbook in the clinical management of patients with anorexia nervosa.

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Managing Severe and Enduring Anorexia Nervosa
A Clinician’s Guide

Edited by Stephen Touyz, Daniel Le Grange, J. Hubert Lacey, and Phillipa Hay
Dedications

To my wife Wren, whose unwavering love and support has become the rock upon which my career has been built. To my children, Justin and Lauren, for their unconditional love, encouragement, and support. To Alex Winkler for both his enthusiasm and invaluable computer skills. Finally, to my patients, who provide me with the inspiration to constantly seek answers where they currently do not exist.

Stephen Touyz

This one is for Tom.

Daniel Le Grange

Whatever I have achieved would never have happened without the love and massive support of my wife, Sue. I dedicate this book to her and to our children, Emma, Ben, and Joff, all of whom have followed me into medicine. Finally, I thank my patients over 46 years who have generously allowed me to research into difficult areas of their lives, on which this work is based.

J. Hubert Lacey

To Anne Hall and Kevin Pile.

Phillipa Hay
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Foreword

This volume is overdue and timely. It is overdue because, as will be noted, anorexia nervosa has long been recognized to be severe and enduring. It is also timely as only in recent years have clinicians and investigators begun to focus explicitly on the impressive persistence of this problem.

Anorexia nervosa is enduring in at least two ways. It is a syndrome whose remarkably homogeneous features have been literally apparent for centuries. Rudolph Bell’s provocative *Holy Anorexia* (Bell, 1985) makes a compelling case that a number of Italian saints of the middle ages who engaged in extreme fasting as an expression of religious self-denial and piety might now be viewed as having anorexia nervosa. It was several centuries later that anorexia nervosa became understood as an illness. In 1789, Richard Morton described an 18-year-old girl with what he termed “nervous consumption.” He clearly distinguished this young woman’s problem from the many forms of infectious disease that were untreatable in his day (tuberculosis was long known as consumption), and emphasized her striking psychological and behavioral features. A century later, in 1873, Sir William Gull (Gull, 1997) coined the term “anorexia nervosa” in a description of young women who would clearly meet all the subsequent formal criteria developed in the various editions of the ICD and the DSM, including ICD-10 and DSM-5.

The key clinical features of anorexia nervosa are stunningly enduring and stunningly homogeneous. The earliest descriptions emphasize, as do current accounts, the remarkable voluntary restriction of energy intake, the physical wasting, and the intense belief that the maintenance of this perilous physical state is somehow preferable and provides evidence of one’s self-worth. What appears most malleable is the psychological rationale for the behavior, ranging from religious piety to secular attractiveness.

Anorexia nervosa is also frequently enduring in its course among individuals who develop it, and, especially among those who are chronically ill, it can be severe. In recent decades, a consensus has gradually emerged, in part due to the development and promulgation of family-based treatment, that early intervention is capable of producing lasting recovery in many, if not most, adolescents presenting with anorexia nervosa. Although
definitive information is difficult to acquire, the long-term mortality of this illness remains as high as that associated with any psychiatric illness. Steinhausen’s (Steinhausen, 2002) assertion that the outcome of anorexia nervosa did not improve substantially in the last half of the twentieth century likely applies as equally to the first decades of the twenty-first century.

Recognizing the critical importance of persistence, clinicians and investigators have begun to focus on factors that sustain anorexia nervosa once it has begun. It is critical to emphasize that the factors that sustain it are likely distinct from those that contributed to its beginning. Hence, it is useful to consider the stages of development of anorexia nervosa, and to adjust treatment methods accordingly. Many interventions that are useful for a 15-year-old girl who has been ill for only a few months are probably not of great benefit to a 45-year-old woman 30 years after the onset.

The chapters in this book grapple with critical facets of severe and enduring anorexia nervosa. How, precisely, should this stage of illness be defined: how ill is “severe,” how long is “enduring?” Many chapters struggle with clinical challenges: what, exactly, are the goals of treatment after years of chronic suffering? What do we know about the utility of treatments, social, psychological, and pharmacological, at this stage of illness? What factors contribute to the persistence of this illness, especially in light of the fact that many individuals who develop anorexia nervosa do not become chronically ill but make complete recoveries? Is it ever appropriate to cease treatment?

Unfortunately, there are no clear answers to these questions. But the contributors to this book, including an individual who provides a valuable account of her personal struggle with anorexia nervosa, provide a definitive and current report of where we now stand. This information constitutes a crucial foundation for much-needed additional work in the years ahead.

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This book is the outcome of our goal to create the first multi-authored authoritative clinical handbook devoted entirely to the understanding and treatment of patients with severe and enduring anorexia nervosa (SE-AN). The inspiration for this emanated from the very encouraging data that emerged from the first randomized clinical trial (RCT) comparing Cognitive Behavior Therapy (CBT) with Specialist Supportive Clinical Management (SSCM) in patients with SE-AN at one treatment site in Sydney, Australia, and another in London, United Kingdom. Our esteemed colleagues, who have so generously contributed to this book, are without doubt the leading experts on the topic of SE-AN today. They have produced chapters of exceptional quality and breadth.

Few would argue that those patients with SE-AN merit our research and clinical attention, not only because they have the highest mortality rate of any mental illness, but suffer from significant medical and psychiatric morbidities as well. Consequently, such patients present with one of the most challenging disorders in mental health care. They have significant disabilities, often under- or unemployed, supported by government-funded health benefit plans and can become a significant burden to parents, carers and health-care funding bodies. Moreover, patients with SE-AN pose significant challenges to those clinicians who undertake to treat them. Some health insurers decline treatment for such patients, arguing that there is no evidence base to support such treatment, while others are declined admissions to specialist eating disorders services for their perceived lack of motivation to change.

There is now a growing interest by clinicians and researchers alike for the most up-to-date information pertaining to the treatment of those with SE-AN. This was further evidenced by the first keynote address on the topic at the 12th International Eating Disorders Conference in London, where Michael Strober, PhD, spoke about “The enduringness of adversity: New vistas for theory and treatment in eating disorders.” Workshops and plenary papers on this topic by the editors of this book were also presented at the Academy of Eating Disorders International Conferences in New York and Boston, the London Eating Disorders Conference,
and the Eating Disorders Research Society meetings in Portugal and Italy. This text endeavors to draw together not only the latest research on this topic, but also provides an informative clinical handbook for those who wish to take up the challenges involved in treating patients with such long-standing illness.

Successfully completing a multi-authorship endeavor such as this one inevitably relies on the expertise of an outstanding editor. We were most fortunate to have one of the best in the business and would like to express our gratitude to Christopher Teja at Routledge, whose enthusiasm, commitment to detail, and ongoing editorial support has ensured that we not only produced the first multi-authored informative clinical handbook on SE-AN, but published it within the agreed timeframe. This was no small feat.
What Do We Know About Severe and Enduring Anorexia Nervosa?

Anna C. Ciao, Erin C. Accurso, and Stephen A. Wonderlich

The persistence of anorexia nervosa (AN) is well-documented in the literature. Even with psychological or pharmacological treatment, many individuals with AN do not recover (Berkman, Lohr & Bulik, 2007). Approximately 20–25% of patients with AN do not remit over the long term (Berkman, Lohr & Bulik, 2007; Steinhausen, 2002). This subset of individuals with persistent AN is often labeled by providers as “chronic” (i.e., long course of disorder), or alternatively “treatment resistant” or “non-responsive” (i.e., failure to achieve good treatment response). Recent literature describes these patients as having “severe and enduring” anorexia nervosa (SE-AN), based in part on evidence that individuals with SE-AN exhibit long-term impairment in physical, psychological, and social domains that parallels other severe and chronic mental disorders such as schizophrenia (Arkell & Robinson, 2008; Steinhausen, 2002).

Clinicians will likely encounter patients with SE-AN in clinical practice, but little research is available to guide best practices for their treatment. This chapter will synthesize available theoretical and empirical knowledge of SE-AN to highlight current knowledge about this clinical population. Therefore, we will first examine how SE-AN is defined and discussed in the literature. We will then review both the empirical literature and theoretical perspectives on the psychosocial treatment of SE-AN, including a randomized-controlled trial comparing two treatments for SE-AN (Touyz et al., 2013), two case-series studies (Golan, 2013; Williams, Dobney & Geller, 2010), and clinical descriptions of intervention strategies (Goldner, 1989; Hamberg et al., 1989; Robinson, 2009; Strober, 2004; 2009; Vitousek, Watson & Wilson, 1998; Yager, 1992). Our conclusions and recommendations reflect the areas of convergence between empirical data and theoretical perspectives.

Defining SE-AN

Although the body of literature dedicated to treatment for SE-AN has grown in recent years, there is a remarkable lack of consensus about how to best define this population. Given the lack of empirical
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research to guide classification, SE-AN has been operationalized in several different ways by various research groups and clinicians. Early theoretical perspectives highlighted motivational aspects of AN that could impact a patient’s ability to benefit from treatment, such as “treatment resistance” (Hamberg et al., 1989; Vitousek, Watson & Wilson, 1998) and “treatment refusal” (Goldner, 1989). Others included an additional focus on chronicity, describing patients as “chronic and recalcitrant” (Yager, 1992), “chronic, treatment-resistant” (Strober, 2004; 2009), or as having “longstanding” eating disorders that “have not benefitted from traditional [treatment] approaches” (Williams, Dobney & Geller, 2010, p. 247). Although these definitions are helpful in characterizing the clinical features of SE-AN, they are too broad to objectively identify patients with SE-AN.

Alternative definitions of SE-AN have utilized the duration of the disorder as an objective and specific marker of chronicity, given the negative relationship between duration of the psychopathology and long-term recovery in AN (for example, Fichter, Quadflieg & Hedlund, 2006; Strober, Freeman & Morrell, 1997). For example, a recently completed randomized-controlled trial comparing two treatments for SE-AN only included participants if they had experienced more than seven years of the disorder (Touyz et al., 2013). The authors note that their cut-off was conservatively derived from the upper limit of average illness length reported in previous AN treatment trials. Others offer a broader definition that includes chronicity along with other factors. In his book discussing the clinical management of severe and enduring eating disorders, Robinson (2009) suggests that SE-AN should be defined by both chronicity and clinical severity. Robinson defines chronicity as a duration of illness greater than ten years, based on Steinhausen’s 2002 findings that recovery rates in AN are slower after that time. Robinson’s operational definition for severity is less clear. While severity is described as the point at which symptoms cause significant impairment to quality of life, this construct is not defined or quantified any further. In her case series report on a comprehensive treatment approach for severe and debilitating eating disorders, including SE-AN, Golan (2013) offers another broad definition. In this study, SE-AN is described as a combination of clinical severity (“difficulty in maintaining regular functioning”), treatment failure (“failed to reach sustained improvement with previous ED treatment”), and chronicity. While Golan provides some data regarding this definition (for example, the average illness duration in the SE-AN sample was 5.7 years with a median of 1.5 months of prior hospitalization and 5 months of prior outpatient treatment), no explicit operational cut-offs for these dimensions of SE-AN are offered.

Challenges in Defining SE-AN

While chronicity, severity, and treatment resistance may all be potentially important in a comprehensive definition of SE-AN, the operationalization
What Do We Know About SE-AN?

of these constructs and their relative weight in defining SE-AN remains unclear. A Delphi study highlighted the challenge of reaching consensus about SE-AN (Tierney & Fox, 2009). Fifty-three eating disorder specialists provided feedback on the definition and treatment of “chronic AN.” Although experts agreed that the definition should include “entrenched patterns of behavior,” an “identity intertwined with AN,” and low weight (BMI < 17.5), they were unable to agree on the importance of other markers of severity (impairment in menstrual or social functioning), chronicity (duration of illness), or treatment response (number of failed treatment attempts).

In addition to the lack of expert agreement, there are several practical challenges that complicate the definition of SE-AN. Even if there is agreement on the domains most relevant to SE-AN (for example, severity, chronicity, and treatment resistance), specific operational definitions must be proposed and consistently applied. This represents a difficult task because some of these indicators of possible SE-AN are not clearly defined. For example, duration of illness is frequently examined in relation to AN prognosis or treatment outcome (Treasure, Stein & Maguire, 2014), yet most studies do not report how illness duration is defined and assessed. In our clinical and research experience, illness duration can be measured in a variety of ways, for example, through patient/family-reported diagnosis date, patient/family-reported date of symptom emergence, or date of entry into treatment. In addition, these definitions do not account for periods of recovery (for example, for an individual who developed AN at age 13, responded well to treatment shortly thereafter, and relapsed at age 20, a seven-year duration of AN would not adequately capture the length of her active disorder). The same measurement issues are present for other constructs, such as how to define a treatment failure or success.

Another challenge is the importance of developmental considerations. For instance, the prognosis and response to active treatment for weight regain of a 20-year-old with a 10-year duration of illness and 47-year-old with a 10-year duration of illness might be significantly different, and it may not be appropriate to label both patients as having SE-AN. A final challenge in defining SE-AN is choosing appropriate clinical severity markers, given the clinical heterogeneity of the SE-AN population. If impairment is seen across psychological, social, and physiological domains it is difficult to identify which clinical symptom areas are most critical in characterizing a severe and enduring course. For example, it is possible that a patient has chronic impairments in medical status but is relatively high-functioning in terms of occupational and social roles. Focusing directly on eating disorder-related symptoms is just as complex since patients with AN may improve on one dimension (for example, report little impairment in cognitive domains of the eating disorder) but exhibit severe impairment in another dimension (for example, chronic low BMI of 16.5). Altogether, the complexity of selecting, operationalizing, and assigning a relative weight
to each of these constructs has delayed the field in reaching consensus on how to comprehensively and specifically define SE-AN.

It is critical to reach consensus on the important elements that define SE-AN, but it is equally important to clearly operationalize each of its elements. This ambiguity and dearth of knowledge about the SE-AN population have led to calls for research that seeks to identify clinical symptoms that differentiate individuals with SE-AN from more acute cases, as well as examine the prognostic value of specific characteristics (Wonderlich et al., 2012). It is apparent that research about SE-AN will continue to advance slowly without a clear sense of the population of interest. Therefore, we restate the need for additional research to inform the definition of SE-AN.

**Treating SE-AN**

**Evidence Base for the Treatment of SE-AN**

While there is agreement that available treatments should be modified to fit the unique needs of an SE-AN population, particularly given the high rates of dropout in AN treatment (DeJong, Broadbent & Schmidt, 2012), there is limited empirical research to guide these recommendations. Indeed, the evidence base for SE-AN treatment is quite limited. Nevertheless, several recent case-series studies and one randomized-controlled trial provide preliminary data on the potential benefit of specific psychological approaches.

*The Community Outreach Partnership Program (COPP); Williams, Dobney, & Geller, 2010*

This case-series report describes a team-based approach for SE-AN and other chronic eating disorders, which includes hospital and community-based services. COPP diminished the importance of reducing or eliminating eating disorder symptoms as treatment goals and instead focused on increasing quality of life by promoting autonomy, increasing hope, and improving psychosocial skills. Outcomes were examined for 31 patients (15 with an AN diagnosis; $M_{\text{age}} = 31.1$ years, $M_{\text{duration of illness}} = 15.2$ years) who participated in the program for approximately two years ($M_{\text{duration}} = 25.6$ months, range: 4 to 53 months). Results indicated that COPP participants experienced significant improvements in global distress, hopelessness, body mass index, and eating disorder symptoms. There were no significant changes in quality of life, which was surprising given that this was the primary target of this program.

*Integrative approach; Golan, 2013*

This case-series report describes a collaborative treatment approach for SE-AN and other severe and enduring eating disorders, which includes mental health, nutritional, and medical services. Treatment is provided
within a developmental framework of recovery using a traditional cognitive-behavioral approach enhanced with narrative therapy and motivational interviewing techniques. Treatment is focused on increasing patient empowerment and achieving collaboratively determined goals. Areas other than the eating disorder are emphasized, such as social skills training and increasing leisure activities. A large number of patients with SE-AN (N = 258; defined as severely ill patients with an illness duration of 6–7 years who had failed to reach sustained improvement with previous eating disorder treatment) were treated in this program with low dropout (8% dropout within the first two months of treatment). Treatment ranged from 15 months to 4 years. At the end of treatment, 69% of those with AN were fully recovered (defined as 12 months of being within 15% of ideal body weight, regular menstruation, no purging behavior, normal eating habits, and good social adjustment) or much improved (defined as having full occupational and social functioning and infrequent eating disorder symptoms). At 4-year follow-up, 68% of those with AN were fully recovered or much improved.

Cognitive Behavioral Therapy (CBT-AN) and Specialist Supportive Clinical Management (SSCM); Touyz et al., 2013
The sole randomized-controlled study within an SE-AN population compared the relative efficacy of CBT-AN to SSCM for 63 adults (M age = 33.4 years, M illness duration = 16.6 years). CBT-AN (adapted for SE-AN from Pike et al., 2003) and SSCM (adapted for SE-AN from McIntosh et al., 2006) differed in style and structure; CBT-AN targeted the key behavior and cognitions of AN, whereas SSCM was more psychoeducationally-focused and supportive. Both treatments were delivered from a harm reduction perspective, not mandating weight gain and instead focusing on improving quality of life. Retention in the study was excellent (87.3% completed treatment, 71.4% completed 6-month follow-up, and 79.4% completed 12-month follow-up). Patients received 30 individual outpatient treatment sessions over eight months. All treatment goals were collaboratively determined by the patient and therapist. At the end of treatment, no treatment differences were found in quality of life, mood disorder symptoms, and social adjustment (primary outcomes) or in weight, eating disorder pathology, motivation for change, and health care burden (secondary outcomes). At 6-month follow-up, participants treated with CBT-AN had greater social adjustment than those treated with SSCM, and at 12-month follow-up the CBT-AN group had lower eating disorder pathology and greater readiness for recovery relative to SSCM.

Areas of Consensus in SE-AN Treatment Approaches
The evidence base described can be combined with several clinical perspectives (Goldner, 1989; Hamberg et al., 1989; Strober, 2004; 2009;
Put Together a Team

There is agreement among perspectives that the multidisciplinary team is fundamental for providing support and stability in the treatment of SE-AN. Team members include the mental health professional, who may also serve as the care coordinator or as primary psychotherapist (Robinson, 2009; Strober, 2004; 2009; Williams, Dobney & Geller, 2010), a physician to monitor medical stability, and a psychiatrist and dietician as needed. Regular communication among team members is mandatory and regular team meetings are encouraged, as well as specific consultation when difficult situations arise (Hamberg et al., 1989; Yager, 1992). There is also a clear emphasis in such team-oriented perspectives to avoid punitive interventions (Goldner, 1989), and to support team members and avoid countertransference problems (Hamberg et al., 1989; Strober, 2004; 2009). Many experts also recommend family involvement in the treatment team (Goldner, 1989; Hamberg et al., 1989; Robinson, 2009). Family members may collaborate on the treatment plan and benefit from specific support services while caring for the patient (Golan, 2013; Robinson, 2009; Strober, 2004; 2009). It may also be necessary to expand the multidisciplinary team at crisis points (Hamberg et al., 1989) or to deliver novel interventions (Yager, 1992). Golan (2013) also describes the use of “clinical mentors” for patients needing increased emotional and functional support.

Move the Goalposts

There is also agreement among approaches that traditional goals in eating disorders treatment are not suitable for patients with SE-AN. Approaching treatment from a traditional framework is likely to increase treatment dropout, and therefore therapists must adjust their expectations at the outset of treatment. Therapeutic goals should be collaboratively determined based on achievable, realistic changes (Strober, 2004; 2009; Yager, 1992). Therapists should directly acknowledge and address any discrepancies between therapist and patient treatment goals (Strober, 2004; 2009). Yager (1992) discusses the common clinical tension between passivity (i.e., setting goals too low) and aggression (i.e., setting goals too high), encouraging clinicians to be self-aware and monitor their reactions as they negotiate goals. Although goals are tailored to fit each patient’s specific needs, homeostasis is not endorsed; change in one or more areas should be encouraged (Vitousek, Watson & Wilson, 1998; Yager, 1992), with the understanding that readiness for change may depend on stage of recovery (Golan, 2013).
Perhaps the largest goal shift relative to traditional eating disorder treatment is the recommendation to minimize the importance of weight gain in an SE-AN population (Hamberg et al., 1989; Strober, 2004; 2009; Touyz et al., 2013). Vitousek and colleagues offer a slightly different perspective, stating that weight gain should remain a primary goal and that treatment should encourage small steps toward that goal (Vitousek, Watson & Wilson, 1998). Lowered expectations for weight gain are often discussed within a harm reduction model (Strober, 2004; 2009; Williams, Dobney & Geller, 2010), with the intent to reduce harm from existing eating disorder behavior while minimizing patient distress over weight gain expectations. One example of a treatment goal based on harm-reduction principles would be achieving medical stability at a low minimum weight (Williams, Dobney & Geller, 2010). When the importance of weight gain is minimized, treatment can focus on other areas, such as achieving nutritional improvement that is unlikely to impact weight (Strober, 2004; 2009) or addressing factors that maintain the eating disorder, such as temperament or maladaptive cognitions (Strober, 2004; 2009; Touyz et al., 2013). A primary focus on non-eating disorder outcomes is also recommended, including improving functioning and quality of life by increasing social and leisure activities, improving self-care, and increasing independence and hope for the future (Golan, 2013; Strober, 2004; 2009; Touyz et al., 2013; Williams, Dobney & Geller, 2010; Yager, 1992). Several perspectives promote comprehensive psychosocial interventions across multiple domains: psychological, medical, family, occupational/academic, social, housing, and financial (Robinson, 2009; Williams, Dobney & Geller, 2010).

Focus on Alliance

There is consistent agreement across perspectives that the collaborative processes requires a strong therapeutic alliance between the therapist and patient with SE-AN. This can be done by establishing a therapeutic environment of patience, respect, and autonomy (Goldner, 1989), validation and empathy (Vitousek, Watson & Wilson, 1998), and acceptance (Hamberg et al., 1989; Strober, 2004; 2009; Vitousek, Watson & Wilson, 1998). Golan (2013) describes the process as “empowering patients and striving to help them achieve what is important for them” (p. 4). Clinicians may choose to build alliance by providing a strong treatment rationale (Goldner, 1989) and exploring past treatment experiences in order to understand current treatment ambivalence or pessimism (Goldner, 1989; Hamberg et al., 1989; Yager, 1992). In dealing with treatment ambivalence, power struggles should be avoided (Goldner, 1989; Vitousek, Watson & Wilson, 1998). Alliance can be prioritized by using Socratic questioning to highlight patient values (Vitousek, Watson & Wilson, 1998) or taking a motivational interviewing stance (Golan, 2013;
Goldner, 1989; Touyz et al., 2013; Vitousek, Watson & Wilson, 1998; Williams, Dobney & Geller, 2010). The increased focus on the therapeutic alliance may help to increase patients’ adherence to treatment and serve as a foundation in which change can occur (Touyz et al., 2013; Yager, 1992). Data suggest that patients with SE-AN can form strong therapeutic alliances across different treatments (Stiles-Shields et al., 2013).

**Set Appropriate Limits**

Although collaboration is encouraged as a primary approach, limit-setting is recommended as an essential tool to address treatment adherence and to ensure patient safety. Setting clear limits from the outset of treatment is critical, particularly requirements for medical safety monitoring and the establishment of clear criteria for medical stabilization. Flexible treatment contracts or care plans can help to create clear treatment expectations (Hamberg et al., 1989; Robinson, 2009; Yager, 1992) and serve as a reference point for discussions around non-adherence. The treatment team should communicate “serious intent and commitment” to patients (Yager, 1992) but be careful to avoid “battles” for control (Goldner, 1989; Vitousek, Watson & Wilson, 1998; Yager, 1992) or make punitive decisions (Goldner, 1989; Vitousek, Watson & Wilson, 1998; Yager, 1992).

In the case of patient non-adherence, clinicians may decide to withdraw active treatment (Goldner, 1989; Williams, Dobney & Geller, 2010; Yager, 1992). Yager (1992) discusses the importance of supporting family members to accept decisions for nonintervention. Yager and Goldner both discuss the process of weighing risks versus benefits of continued intervention, recommending continued intervention as long as a small benefit exists (Goldner, 1989; Yager, 1992). Yager (1992) also discusses palliative approaches for the patient who is not responding to any intervention and whose illness will be life-limiting, although other perspectives discourage palliative treatment (Williams, Dobney & Geller, 2010) and focus on continuing to encourage change or withdrawing treatment. Alternatively, clinicians may consider involuntary commitment; legal support for such decisions may be warranted (Goldner, 1989; Yager, 1992).

**Areas Where Consensus is Unclear**

The Delphi study on SE-AN provides some evidence that experts agree on many essential components of SE-AN treatment, such as establishing a good therapeutic relationship, creating joint treatment goals, and taking “small steps” toward goals (Tierney & Fox, 2009). However, experts debated the importance of other aspects of treatment, for example, family involvement and social skills training (Tierney & Fox, 2009). Our review of the literature also suggests there is no consensus about the appropriate treatment setting for patients with SE-AN. Many advocate that outpatient
settings are appropriate as long as medical stability is maintained (Golan, 2013; Goldner, 1989; Hamberg et al., 1989; Robinson, 2009; Touyz et al., 2013; Vitousek, Watson & Wilson, 1998; Yager, 1992). Goldner (1989) believes that outpatient treatment is necessary to enhance patient control and autonomy, which are essential for recovery. In contrast, Strober (2004; 2009) advocates for specialist inpatient hospitalization, claiming that the comprehensive, coordinated care required to treat SE-AN is best provided in an inpatient setting. Strober acknowledges that patient access to inpatient treatment can be limited by institutional and health care restrictions, and that well-coordinated outpatient treatment would be suitable in these cases. An intermediate perspective is evidenced by COPP (Williams, Dobney & Geller, 2010), which provides services on an outpatient basis with readily available inpatient services provided by the same treatment team. The COPP approach can also offer specialized medical interventions on an outpatient basis (for example, nasogastric refeeding). Clearly, the differences in recommended treatment settings by different clinicians speak to the absence of a well-defined and integrated approach to treating SE-AN and likely underscore the clinical reality that SE-AN patients will utilize a range of levels of care over the course of treatment, which is by definition, lengthy.

Conclusion and Recommendations

The goal of this chapter was to summarize what we know about SE-AN. In short, there are many unanswered questions. Although clinical approaches for SE-AN converge around several themes, there is limited empirical research to support these recommendations. Moreover, it is still unclear how to define SE-AN and apply this definition consistently, which in turn interferes with determining which patients are appropriate to receive treatments designed for SE-AN. Although there appears to be theoretical consensus that SE-AN is a distinct clinical population in need of tailored treatment approaches, there is little empirical information to support this claim. It is crucial for clinicians and researchers to collaborate on developing an empirically-informed operational definition for SE-AN to facilitate future research. Once the SE-AN population is better defined and its specific psychopathology elucidated, treatments can be further tailored to target the mechanisms that sustain a severe and enduring course.

We propose that this can be accomplished by conducting research that more clearly characterizes individuals with SE-AN. Research should seek to understand the potentially important facets of SE-AN highlighted in this chapter that may distinguish SE-AN, such as duration of illness, past treatment attempts, and clinical severity. It is particularly important to understand how these constructs differentially impact treatment response in AN. If SE-AN is a unique diagnosis marked by these characteristics, we would expect to see these variables emerge as significant predictors of
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outcome in AN treatments. While some of this information, particularly duration of illness, is routinely examined in adolescent AN trials (for example, Le Grange et al., 2012), these analyses are largely absent in adult AN trials (for example, Dare et al., 2001; McIntosh et al., 2005; Pike et al., 2003). Although longitudinal research does suggest that longer duration of AN illness is related to worse prognosis over the long term (for example, Fichter, Quadflieg & Hedlund, 2006), it is not clear what predictive validity the various features of SE-AN show in terms of treatment outcome. Indeed, duration of illness was not found to significantly predict treatment outcome in one treatment trial for adult AN (Lock et al., 2013).

Nevertheless, we are encouraged by the recent growth in treatment research for SE-AN, including a treatment trial suggesting that patients with SE-AN can achieve positive changes during treatment (Touyz et al., 2013). It has been speculated that widening the set of treatment goals for patients with SE-AN helps to increase engagement and motivation, which in turn promotes improvement in symptoms and functioning (Touyz et al., 2013). Qualitative research on women recovered from SE-AN suggests that recovery is a developmental process during which motivation reaches a “tipping point” when patients are ready for intervention and possible change (Dawson, Rhodes & Touyz, 2014). Treatment that is collaborative in nature, fosters a strong therapeutic relationship, and focuses on treatment goals other than eating disorder symptoms, may be useful in engaging patients in treatment, which ultimately may help them to reach this “tipping point” and achieve change. However, in order for future treatment studies to have a more meaningful impact, this population first needs to be more carefully defined.

References


What Do We Know About SE-AN?


Quality of Life and Psychosocial Functioning in Severe and Enduring Anorexia Nervosa

Debra L. Franko, Helen B. Murray, Christopher J. Mancuso, and Kamryn T. Eddy

Psychosocial functioning and quality of life have been topics of study in eating disorders for a long time (Miller, 1996; Schwartz & Thompson, 1981). These issues are of great interest because an understanding of the broader implications of life with an eating disorder is important for ongoing clinical work and the development of interventions that address concerns beyond symptomatology.

Most early outcome studies in eating disorders focused on physical symptoms, for example, weight and menstrual status, more so than quality of life. In a review, Fisher (2003) concluded that although outcomes related to weight restoration and nutritional status in anorexia nervosa are clear, “psychiatric outcome and psychosocial functioning are much more complicated.” Based on recommendations from researchers to better capture change (or stagnation) in patients’ quality of life over time (for example, Herzog, Keller & Lavori, 1988; Schwartz & Thompson, 1981), Fisher (2003) advised that a greater breadth of variables be considered when studying outcome in eating disorders, including “mental health status, educational and vocational achievement, social and family relationships, and psychosexual functioning” (p. 157).

In recent years, research has focused on a more comprehensive examination of quality of life in women with eating disorders. Quality of life has been studied primarily with six instruments, including four that are eating disorder-specific and two that are more general. The Eating Disorders Quality of Life Instrument (EDQOL) is a 25-item, self-report questionnaire that covers four domains, including psychological, physical/cognitive, financial, and work/school functioning (Engel et al., 2006). The Eating Disorders Quality of Life Scale (EDQLS) is a 40-item, self-administered scale designed to assess adolescents and adults with eating disorders across 12 domains (Adair et al., 2007). The Health-Related Quality of Life in Eating Disorders Questionnaire (HeRQoLEDv2) is available in English and Spanish and examines the impact of an eating disorder diagnosis across a number of domains (Las Hayas et al., 2006). The Quality of Life for Eating Disorders (QOL ED) is a 20-item self-report questionnaire that was developed and validated...
to assess health-related quality of life across six domains (Abraham et al., 2006). The Medical Outcomes Study Short Form: version 2 (SF-36; Ware, Kosinski & Keller, 1996) is a well-validated and widely used measure of health-related quality of life that includes eight subscales (four for physical health, four for mental health) as well as a physical health summary score and mental health summary score. The World Health Organization Quality of Life (WHOQOL)-BREF (The WHOQOL Group, 1998a) is an abbreviated version of the WHOQOL-100 (The WHOQOL Group, 1998b). This 26-item questionnaire assesses quality of life in the past four weeks in four domains: physical health, psychological health, social relationships, and environment. Each of these six instruments vary with regard to which specific domains are assessed, the time period of recall, the demographics and diagnostic category of the sample used to validate the measure, and whether the quality of life questions are written in general terms (i.e., SF-36 and WHOQOL-BREF) or ask more specifically about quality of life in relation to the eating disorder (i.e., EDQOL, EDQLS, HeRQoLEDv2, and QOL ED). Choice of instrument varies by study, though few authors provide the rationale for choosing one measure over another. Studies using these measures have included inpatient, outpatient, and community samples of patients with eating disorders, and findings from representative studies will now be highlighted.

**Quality of Life in Eating Disorders**

Engel and colleagues (2009) provided a comprehensive review of quality of life in eating disorders, identifying six themes that emerged in the literature across 25 studies. They concluded that quality of life is: (1) lower in eating disorder patients relative to controls; (2) impaired also in individuals with subthreshold eating disorders; (3) negatively impacted in caregivers of those with eating disorders; (4) comparable to those with serious medical illness and other psychiatric disorders; (5) likely to improve with treatment; and (6) impacted by gender, with quality of life in women being more negatively affected by the eating disorder than quality of life in men, on the basis of two studies.

More recently, published studies echo these themes and draw similar conclusions. For example, a recent meta-analysis (Winkler et al., 2014) of seven studies (n=227 anorexia nervosa; n=216 bulimia nervosa; n=166 eating disorder not otherwise specified [EDNOS]; n=148 binge eating disorder) found lower health-related quality of life relative to the population mean as measured by the SF-36. Interestingly, no differences were found among four diagnostic groups on any of the eight subscales. On the physical health subscales, the mean scores on the physical functioning and bodily pain scales were similar to population norms, whereas the scores on the role limitations due to physical health and general health perception scales were lower than population norms. With regard to the mental health
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scores, all four subscales were lower in the eating disorder groups relative to the population norms (vitality, social functioning, role limitations due to emotional problems, and general mental health). Body mass index (BMI) was not found to be related to quality of life in this study.

Latner et al. (2013) also used the SF-36 to compare health-related quality of life in a sample of women with eating disorders from an outpatient clinic (n=53) to a non-clinical sample of women from the community (n=214). Compared to the community sample, women with eating disorders had significantly poorer quality of life on all of the SF-36 subscales. Eating disorder behavior (based on Eating Disorder Examination-Questionnaire; Fairburn & Beglin, 1994) significantly predicted poorer quality of life in mental and physical domains, primarily due to extreme weight and shape concern. Shape and weight concerns independently predicted poorer quality of life across all SF-36 subscales except for bodily pain. Finally, in contrast to Winkler et al. (2014), Latner et al. (2013) found that BMI predicted poor quality of life scores for physical functioning.

In a smaller study (Baiano et al., 2014), 80 female eating disorder patients (both inpatients and outpatients) with current DSM-IV diagnosis of anorexia nervosa (n=33), bulimia nervosa (n=26), binge eating disorder (n=7), or eating disorder not otherwise specified (n=14) completed the WHOQOL-BREF (Skevington, Lotfy & O'Connell, 2004). Findings indicated that compared to population norms, the eating disorder groups reported poorer quality of life scores, which were particularly pronounced for the mental health components of this scale. Although symptom improvement was correlated with improvement in quality of life, duration of illness was not. The only difference between diagnostic groups was found on the psychological subscale of the WHOQOL-BREF, which measures body image, positive and negative feelings, self-esteem, spirituality and personal beliefs, and cognitive functioning (thinking, learning, memory, and concentration), in which those with EDNOS were found to be less impaired than those with anorexia nervosa, bulimia nervosa, or binge eating disorder.

In the largest study to date, Mitchison et al. (2015) reported on data from a 9-year longitudinal investigation of eating disorder symptoms, quality of life and psychological distress in a community sample of 828 women. They found evidence indicating a significant bi-directional relationship among these variables, such that eating disorder symptoms predicted a lower quality of life and higher psychological distress over the 9-year longitudinal period. In addition, lower quality of life and higher psychological distress predicted higher levels of eating disorder behavior over time. The authors concluded that their data supports “a movement away from symptom-centric approaches whereby HRQoL [health-related quality of life] is conceptualized as a passive outcome expected to be rectified by addressing ED symptoms. Improvement in QoL [quality of life] and PD [psychological distress] might rather be viewed as targets to
be pursued in their own right under broader approaches in the treatment of EDs.” (p. 1)

Recent studies have found greater differences between individuals with eating disorders and healthy controls on the mental health component of quality of life relative to the physical health component. However, few differences among diagnostic groups have been identified. Recent data from a large community sample indicate the reciprocal relationship between eating disorder symptoms and quality of life and some authors have argued that quality of life should be a significant focus of treatment for those struggling with eating disorders.

**Quality of Life in Anorexia Nervosa**

Anorexia nervosa is often considered to be particularly chronic and impairing. For individuals struggling with low-weight eating disorders, with which there is often high medical risk, investigators have examined quality of life in the short and long term. In a study of inpatients with anorexia nervosa (Abbate-Daga et al., 2014), health-related quality of life, as measured by the SF-36, was found to be severely impaired when patients with anorexia nervosa were admitted to an inpatient unit through the emergency room. Improvement was observed at discharge from the hospital and interestingly, quality of life was not found to correlate with eating disorder symptoms or personality characteristics (as measured by the temperament and character inventory; Cloninger et al., 1994). Improvement in quality of life after treatment has been found in other inpatient studies of anorexia nervosa (Abraham et al., 2006; González-Pinto et al., 2004), suggesting that the weight restoration that occurs as a result of hospitalization is associated with better psychosocial functioning, at least concurrently.

In a community-based study of 89 women with lifetime anorexia nervosa (Mitchison et al., 2013), the SF-36 was used to assess quality of life on four physical health scales (physical functioning, role limitations due to physical health, bodily pain, general health) and four mental health subscales (vitality, social functioning, role limitations due to emotional health, mental health). Results indicated that participants with anorexia nervosa scored more poorly than healthy controls on six of eight subscales (not physical functioning or bodily pain) and had lower mental health summary scores than controls. The authors also found that those reporting active eating disorder symptoms had a poorer quality of life than those not currently experiencing symptoms on several subscales (social functioning, role limitations).

The literature to date indicates that quality of life in anorexia nervosa is significantly impaired relative to healthy controls, but not necessarily more so than in comparison to individuals with other eating disorder diagnoses. Although quality of life and psychosocial functioning appear
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to improve with treatment, to date, no longitudinal studies have been conducted to show whether such improvements are maintained over time. Degree of impairment is greater on the mental health components of quality of life than the physical components in most studies.

Until recently, studies did not consider duration of illness when studying quality of life in women with anorexia nervosa, leaving open questions about whether and when quality of life and psychosocial impairment become compromised in those with anorexia nervosa. Touyz and colleagues (2013) conducted a randomized controlled clinical trial of 63 women with severe and enduring anorexia nervosa (SE-AN), defined by an illness duration of seven or more years. Using this sample, Bamford et al. (2015) asked what clinicians should focus on when treating patients with SE-AN: symptom remission or quality of life? In this multisite treatment trial, quality of life was measured with three scales (EDQOL, Engel et al., 2006; Short-Form 12 Health Status Questionnaire, Ware et al., 1996; Weissman Social Adjustment Scale, Weissman & Bothwell, 1976). The authors examined whether BMI and eating disorder symptoms predicted quality of life in SE-AN patients enrolled in this treatment trial, and found that these variables predicted both current and future quality of life. Further, improvements in BMI and symptoms predicted improvements in quality of life, leading to the conclusion that “shifting the focus of treatment towards a balance between symptom and QoL [quality of life] change may be a more effective way of ultimately achieving improvements in both domains” (p. 137).

Longitudinal Data on Quality of Life in Anorexia Nervosa

We have been interested in psychosocial functioning in women with eating disorders who participated in the Massachusetts General Hospital Longitudinal Study of Anorexia Nervosa and Bulimia Nervosa, which began in 1987 and followed 246 women with eating disorders every six months for nearly ten years (Herzog et al., 1999). The majority (77%) of the cohort was reassessed 25 years later between 2011 and 2013. During the first ten years of the study, the Longitudinal Interval Follow-up Evaluation-Range of Impaired Functioning Tool (LIFE-RIFT; Leon et al., 1999) was used to assess functional impairment. This measure is interview-based and assesses level of impairment in each of the following four domains: work, interpersonal relations, recreation, and global satisfaction, on a scale of 1–5, with 1=no impairment and 5=severe impairment. During the first ten years of the study (Wave I), participants were interviewed approximately every six months, thus obtaining a longitudinal examination of changes in psychosocial functioning over time. At the one-time 25-year assessment (Wave II), participants were interviewed again with the LIFE-RIFT interview. In addition, the WHOQOL-BREF (The WHOQOL Group, 1998a) was completed by the participants. This 26-item questionnaire
assesses quality of life in the past four weeks in four domains: physical health, psychological health, social relationships, and environment. Ratings are given on a 1–5 scale, with higher numbers indicating higher quality of life. The WHOQOL-BREF has been widely used in mental health studies (Johansen et al., 2007 for PTSD; Yen et al., 2009 for depression), as well as one study with an eating disorder sample (Mond et al., 2005). Criterion and content validity, internal consistency, and test-retest reliability have been established (The WHOQOL Group, 1998a).

From our initial sample of 246 women diagnosed with DSM-IV eating disorders (n=136 with anorexia nervosa and n=110 with bulimia nervosa), we focus here on quality of life and psychosocial functioning in those participants with anorexia nervosa who had no periods of recovery over the first ten years of the study (Wave I), and who were not recovered when we reassessed them at Wave II, which occurred 22 years (on average) after study entry. Using the Longitudinal Interval Follow-Up Evaluation Eating Disorders Version (LIFE-EAT II) (Herzog et al., 1999), each participant received a psychiatric status rating (PSR) for both anorexia nervosa and bulimia nervosa symptoms at each visit for the previous six-month period. PSRs are ordinal, symptom-oriented scale scores based on Research Diagnostic Criteria ratings (Spitzer, Endicott & Robins, 1978) on a 1 (no symptoms) to 6 (full criteria, severe symptoms) scale. Scores of 1 and 2 capture recovery from the eating disorder, scores of 3 and 4 capture symptoms equivalent to partial recovery, and scores of 5 and 6 capture symptoms equivalent to meeting full criteria for an eating disorder. More specifically, a PSR score of 1 indicated that the participant was symptom free and a score of 2 indicated body weight at least at 95% of expected and, when applicable, the absence of bingeing or purging behavior, although shape and weight cognitions or urges to binge or purge may still be present. A score of 3 was given when body weight was at least at 90% of expected weight and cognitive symptoms were still present, and, when applicable, bingeing or purging behavior occurred fewer than three times per month. A score of 4 was given for being at least below 90% of expected body weight, but narrowly missing full criteria for anorexia nervosa, and, when applicable, bingeing/purging behavior that occurred more than three times per month but fewer than two times per week. A score of 5 was given for meeting full criteria for DSM-IV anorexia nervosa, and, when applicable, bingeing/purging behavior at least twice per week, and a score of 6 was given for the same symptoms as a score of 5, but when the symptoms were severe enough to warrant inpatient or residential care.

From our original sample of 136 women with anorexia nervosa, we identified a group of women we characterized as chronic, based on PSR scores ≥ 4 steady across Wave I and at Wave II. A few participants included had an anorexia nervosa PSR score of 3 during one time period that was less than six months in length. Fourteen such individuals were
identified, who were on average 49.5 years of age (range 39–63 years) at the Wave II assessment, with a reported average BMI of 15.8 (SD=2.5, range=10.8–18.5). Five of the 14 reported current depression and nine were on psychiatric medications. Of the 14, five had been diagnosed with anorexia nervosa – restricting type – and ten with anorexia nervosa – binge eating/purging type – at study entry. Wave II Eating Disorder Examination-Questionnaire data indicated scores above the clinical cut-off on the Restraint (4.4) subscale and near the clinical cutoff on the Shape Concern (3.7) subscale, but lower scores on the Eating Concern (2.8) and Weight Concern subscales (3.0), as noted in Table 2.1.

We examined the LIFE-RIFT data at yearly intervals for our 14 participants with chronic anorexia nervosa for each focus of inquiry at Wave I, which for most participants was a period of eight–ten years, and then at Wave II (25-year follow-up). As noted, the LIFE-RIFT categories were: employment; household duties; student work; relationships with parents, siblings, mate, friends; recreation; and overall satisfaction with the various areas of functioning in the participant’s life (i.e., the degree to which she thought that her needs and desires were fulfilled). Additionally, interviewers were asked to make an overall rating of psychosocial functioning at the end of the interview.

For the areas of employment/household duties/student work (if applicable), all but three of our 14 participants with anorexia nervosa scored in the very good/good/fair categories across Wave I (8–10 years). There was remarkable stability across the years for most participants, and that stability indicated little impairment in these three areas of psychosocial functioning.

The data were much more variable for the interpersonal areas of functioning. With respect to interpersonal relationships with parents, most participants, across the years, received ratings of very good, good, or fair. Four of the 14 participants had some ratings of poor relationships with parents, although this occurred in a minority of the years for these participants. Relationships with siblings showed considerably more variability within subjects across years, and across the entire sample, relative

**Table 2.1 Wave II Eating Disorder Examination-Questionnaire subscale scores (n=13)**

<table>
<thead>
<tr>
<th>EDE-Q subscale</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restraint</td>
<td>4.4 (2.0)</td>
</tr>
<tr>
<td>Eating concern</td>
<td>2.8 (2.2)</td>
</tr>
<tr>
<td>Shape concern</td>
<td>3.7 (1.5)</td>
</tr>
<tr>
<td>Weight concern</td>
<td>3.0 (1.7)</td>
</tr>
<tr>
<td>Global</td>
<td>3.5 (1.7)</td>
</tr>
</tbody>
</table>

Note: Two participants did not complete the EDE-Q.
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to the ratings for parents. The majority of participants had at least one year, and often more than one, when sibling relationships were rated as poor or very poor, and within participants, ratings across the years often spanned across several categories (from very poor to very good). Relationships with friends were the most variable of interpersonal functioning categories across ten years of data. There were wide ranges (with ratings that sometimes ranged from 1 to 5 over the years) within subjects, and a great deal of variability across the sample, with some participants reporting very good or good relationships with friends across the period of the study, and others showing a highly variable course in their relationships with friends over the years (i.e., ratings of fair, poor, and very poor across a ten-year period). Relationships with mates was most often not applicable during Wave I, as all but two participants were single or divorced.

The prompt about recreational activities asked participants to let the interviewer know the extent to which she had been involved in and able to enjoy recreational activities or hobbies such as reading, sports, gardening, socializing, etc. The responses over the years were highly variable across the sample, with some participants rating their recreational activities as primarily very good or good most years, and others reporting many years of poor or very poor recreational functioning. There was some degree of variability for participants across the years, though most ratings were within two anchor points over the years within subjects. The final area of inquiry focused on the participant’s overall satisfaction with psychosocial functioning, which was prompted as follows:

Satisfaction is intended to convey the subject’s contentment with the various areas of functioning in her life, and not her actual level of functioning. This includes the gratification received from these activities and the degree to which the subject thinks her needs and desires are fulfilled.

Over the Wave I period, ratings on this overall measure of satisfaction from the participants’ perspective showed a variable pattern within and across the sample.

At the end of the interview, the rater was asked to rate the participant in response to the following prompt: “Taking into consideration everything you know about the subject, including education, social background, and the level of functioning in the areas of work, interpersonal relations, and sex, what would you consider her level of social adjustment over each of the past 12 months?” Examination of the interviewer-based ratings over Wave I for the 14 participants revealed that only two participants received ratings of “very good” and this occurred only for a couple of years. Instead, most participants received ratings that ranged from good to fair to poor across the years of study participation. There was significant variability in the interviewer’s overall assessment
of the participants’ psychosocial functioning for most individuals in this subsample.

To summarize the annual interview-based ratings of our subsample of individuals with chronic anorexia nervosa over the first ten years of our longitudinal study, there was relative stability and little impairment in the areas of work (employment or student work) and attending to household duties, but higher variability in the areas of recreational activities. With regard to interpersonal relationships, relationships with parents tended to be better than relationships with siblings or friends, and this was true both within participants and across the entire sample. Very few participants had partners during the time of the study. Both the participants’ ratings and interviewers’ ratings of overall satisfaction with psychosocial functioning suggested a highly variable course over time within participants over the years and variability across the sample along the anchor points of very good to very poor. The overall conclusions to be drawn about psychosocial functioning over this ten-year period would be that it is highly variable, whether examining different categories (for example, work and friends), looking within participants (for example, high variability in ratings for most participants from years 1 to 10), or examining the sample as a whole (for example, some participants did relatively well over the years while others consistently struggled across areas of functioning).

At 25-year follow-up, LIFE-RIFT data indicated improved functioning among this chronically ill cohort. In the areas of employment/household duties/student work, all but three participants received a rating of very good, good, or fair. In terms of relationships with parents, only one participant had a rating of poor; for siblings, four participants had ratings of poor or very poor; and for friends, three participants had a rating of poor or very poor. All other ratings with regard to interpersonal relationships were rated as very good, good, or fair. All but three participants reported the same marital status at the end of Wave I and at Wave II; specifically, at 25-year follow-up, two participants were married and one participant was living with a significant other. On the recreation variable, four of 14 participants were rated as poor or very poor. The overall participant-rated satisfaction was rated as poor for four participants as well. For the overall assessment of psychosocial functioning made by the interviewer, five participants received a rating of poor or very poor, while the remainder (n=10) were rated by the interviewer as very good, good, or fair. Our 25-year assessment data indicated that the majority of the 14 participants were doing quite well in terms of these domains of quality of life. Our results suggested that approximately one-third of the sample struggled with their interpersonal relationships, recreational activities, and overall satisfaction, and the interviewer-based assessment was consistent with this. However, two-thirds of this chronic anorexia nervosa population received ratings indicating they were functioning in the “fair to very good”
range in each of these domains. Based on our ten-year longitudinal data, as well as on our 25-year follow-up data, we conclude that there is not one way to characterize the quality of life and overall psychosocial functioning in our sample of women with chronic anorexia nervosa. Instead, the course was often variable and differed by domain and time frame. In the long term, the majority of our participants were doing well in their psychosocial functioning, despite their continued symptomatology, suggesting that poor quality of life and chronic anorexia nervosa symptoms do not necessarily go hand-in-hand.

The data from the quantitative measure of quality of life underscores these findings. Mean scores on the WHOQOL-BREF for 13 of 14 women with longstanding AN, compared with normative sample data reported in the original WHOQOL-BREF report (Skevington et al., 2004), are shown in Table 2.2. Interestingly, scores for the eating disorder group were all within one standard deviation of the normative group, indicating that the quality of life was not substantially different from population norms matched by age and gender as measured by this scale. These numbers are somewhat surprising, given previous literature indicating significantly poorer quality of life in AN relative to the general population, but are consistent with our interview-based data and may reflect some degree of accommodation to the illness that occurs with time.

In addition to quantitative data, we also obtained some qualitative data at the 25-year follow-up assessment. The narratives provide additional information that is instructive. At the end of the self-report portion of the study, participants were asked to “briefly describe the story of your eating disorder since your last interview.” Of the 14 women with chronic anorexia nervosa, 11 opted to respond to this prompt in the questionnaire. As can be seen from the quotes, their responses often indicated the struggles that women with long-standing anorexia nervosa continued to contend with as related to their quality of life and their eating disorder. However, participants also offered a number of positive comments. We note two themes that emerged in these brief narratives.

Table 2.2 Wave II WHOQOL-BREF mean scores and standard deviations (n=13) and normative data

<table>
<thead>
<tr>
<th></th>
<th>Physical health</th>
<th>Psychological health</th>
<th>Social relationships</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women with anorexia nervosa</td>
<td>12.6 (2.1)</td>
<td>12.0 (1.9)</td>
<td>12.5 (3.7)</td>
<td>15.7 (2.7)</td>
</tr>
<tr>
<td>Women aged 41–50*</td>
<td>13.9 (2.9)</td>
<td>14.0 (2.7)</td>
<td>14.1 (3.1)</td>
<td>13.9 (2.6)</td>
</tr>
<tr>
<td>Women aged 51–69*</td>
<td>13.3 (2.9)</td>
<td>13.8 (2.8)</td>
<td>14.1 (2.9)</td>
<td>14.0 (2.6)</td>
</tr>
</tbody>
</table>

*From Skevington et al., 2004.
Note: One participant did not complete the WHOQOL-BREF.
Qualitative Data

The first theme related to stories women told expressing a kind of acceptance about their eating disorder and the way they had “given up” the idea that their eating disorder would ever not be a part of their lives. For example:

My eating disorder is just a part of my everyday life. I function just fine each and every day, but the quality of my life (the enjoyment of what I do) is greatly burdened by my preoccupation with food. I have given up on trying to rid myself of the eating disorder. I just don’t have the energy to battle it anymore.

I have accepted that my eating disorder will eventually take my life in the near future. I just have to enjoy and try to be strong as much as I can for my kids. I’m not looking for sympathy, I just know that I’ve tried so many different treatments and nothing or no one has helped.

I continue to judge myself based on my weight. It is my litmus for whether I will have a good or bad day. I am able to “fake” it and push through so that people still see me as a happy and functioning member of society!

I am still very careful in what I eat to control my weight. I do not want to lose weight, but do fear gaining weight. I still do not like my body shape.

A second theme emerged as other women spoke about the way that their eating disorder had influenced important areas of their life in relation to their psychosocial functioning, predominantly in the areas of employment and family in relation to their symptoms and struggles. The tenor of these comments was often negative.

I don’t recall when my last interview was, but the past two years have been difficult. Ultimately my performance at work suffered, and the stress of everything caused a relapse of my Crohn’s Disease. I took a leave of absence from my job, and the weight loss started to accelerate. Although my Crohn’s cleared up, I was not motivated to gain weight or return to work. My disability was then changed to depression and an eating disorder. I was hospitalized against my will last December.

Why should I care and worry so much about my weight? 90 lbs feels too heavy. Logically I understand that that is the eating disorder, the eating disorder “talking” to me. But I am unable to turn off
those thoughts as easily as turning off the radio. To end, I am a grandmother of seven ranging in age from 24 down to 22 months and now a great-grandmother of a one-year-old. Because of these kids, as much as I have wanted to sometimes, I continue to fight the eating disorder forever.

Due to life events and demands on my time in the last decade, I grew very badly out of shape. There was little I could do other than accept this and, in a way, face my fears. I continue to wish I could be in ideal shape at a very low weight, but body image concerns have little time in my life. Lately, I have been able to exercise a bit and it has made me feel very positive about myself.

I try to keep my weight within a 5 lb. range and don’t like going below because I feel too weak and tired to do the things I want. Over the past years I have a much better social life and supportive network of friends, acquaintances, and coworkers. I am more satisfied with myself and some of my achievements.

Finally, one of the 14 women wrote positive comments about her life some 25 years after she entered the longitudinal study, commenting on her feelings about her body and changes in her eating behavior and body shape as she aged.

I would not classify myself as having an eating disorder at this point. Have not been hospitalized in 20 years. Almost never binge, do not starve, perhaps vomited five times in past five years (really don’t remember, but it’s rare). I think that finally finding a medication that put a noticeable dent in my depression and anxiety was very helpful. Still experience stress and anxiety (mostly performance-based/anticipatory), but occasional therapy is a wonderful support. Returned to school, have been holding a full-time job since graduation. I feel very grateful!

Clinical Implications

There are several clinical implications that can be gleaned from the literature and our longitudinal data. First, quality of life is impaired across the eating disorders, with limited between-diagnostic group differences. Second, quality of life in chronic anorexia nervosa, as well as in community samples of women with eating disorders, appears to have a bi-directional relationship with symptoms, whereby improvement in one can result in improvement in the other. Third, treatment does appear to improve quality of life. Researchers have recently suggested that quality of life should be a key component of treatment for eating disorders, particularly for those
with long-standing and chronic anorexia nervosa. Fourth, it is possible that the passage of time, independent of treatment, improves symptoms, such that individuals with long-standing anorexia nervosa perhaps become inured to their eating disorder over time, or improve in functioning in spite of continued symptomatology. This may explain our longitudinal data in which quality of life was not terribly impaired at long-term follow-up, despite continuing and chronic anorexia nervosa. Based on our data, albeit from a very small sample, it appears that there are some areas of interpersonal functioning where a longer duration of illness exacerbates psychosocial problems (for example, friendships, romantic relationships), but others where its long-term impact is diminished or at best does not worsen (for example, work). These findings would underscore suggestions by others that quality of life, particularly in the realm of interpersonal relationships, should be as important a part of treatment as managing symptoms. Our longitudinal data argue for attention to quality of life as well as to continued concentration on improving eating disorder symptoms, even for those who have struggled for many years.

References


One approach frequently utilized in the study of psychiatric illness is the exploration of central underlying mechanisms that predispose, precipitate, and perpetuate symptom manifestations. Predisposing factors are considered inherent characteristics that motivate behavior and influence the type and amount of resources an individual can elicit to cope with stress (O’Toole, 2013). An individual’s genetics, gender, age, values and attitudes, personality, culture, and environment affect the way they behave. Understanding these predisposing factors can help identify those stimuli that render an individual susceptible to a psychiatric illness. Precipitating factors are elements associated with or contribute to the onset of the illness. These factors can be biological, psychological, social, or environmental and are considered the catalyst or trigger for the symptom or illness. Perpetuating factors are conditions that maintain the disabling symptoms of the illness. Examining maintenance phenomena can assist in predicting symptom persistence among afflicted individuals and inform the development of more effective treatment interventions (Treasure et al., 2007).

This chapter will focus on perpetuating factors in severe and enduring anorexia nervosa (SE-AN). One caveat should be mentioned. Eating disorder (ED) diagnoses are fluid and exist on a continuum. For example, up to 50% of AN patients will develop bulimic symptoms during the course of their illness (Fairburn, 1995). This chapter will discuss hypothesized perpetuating factors found in both AN-restrictor subtype (AN-R) and AN-binge purge subtype (AN-BP). The chapter begins with a review of the neurobiological factors, genetic factors, psychological factors, cultural factors, social factors, and environmental factors that can maintain ED symptoms and closes with a brief case example that highlights the impact of unresolved perpetuating factors in the treatment of severe AN.

**Neurobiological Factors**

**CNS Endogenous Opioids**

One potential perpetuating factor in SE-AN is a dysregulation in the opioid system during active illness. This hypothesis was derived from theories...
Perpetuating Factors in SE-AN

based on self-starvation in animals. Early animal researchers discovered that rats with restricted access to food run much more than rats that have open access to food (Bolles & de Lorge, 1962; Hall & Hanford, 1954; Spear & Hill, 1962). Routtenberg and Kuznesof (1967) furthered this research into self-starvation in rats and discovered that weight loss was accompanied by more intense running, to the point that many rats, with unrestricted access to running, died. This phenomenon was later termed “activity-based anorexia” (ABA) and used to describe running-based weight loss (Epling, Pierce & Stefan, 1983). These discoveries laid the foundation for researchers interested in self-starvation in AN. Since the mid-1980s, ED researchers have been interested in the “auto-addiction” opioid model of chronic AN (Luby, Marrazzi & Sperti, 1987; Marrazzi & Luby, 1986; Marrazzi et al., 1990; Szmukler & Tantam, 1984). They hypothesized that “endogenous opioids functionally support adaption to starvation by conserving absorbed resources and by the concomitant decrease of the metabolic rate” (Fladung et al., 2010, p. 206) and termed this process “starvation dependence” (Luby, Marrazzi & Sperti, 1987). This model suggests that relentless dieting, the compulsive pursuit of weight loss, continued weight loss even when medically compromised, the ego-syntonic nature of the disorder, and patient reports of starvation-related euphoria may indicate an “auto-addictive” process that is mediated by the endogenous opioid system. They propose that endogenous opiates are released during the initial period of dieting or prolonged food deprivation, which creates a psychological “high” and, in turn, initiates and reinforces a state of starvation dependence. This theory also suggests that individuals with AN may have a malfunction of the neurotransmitter systems that modulate feeding. Early animal studies reported that the opioid peptide dynorphin appears to enhance feeding behavior in rats (Morley et al., 1984) while other opioid systems (such as the stimulation of the mu receptor system) appear to inhibit food intake.

Several studies have been conducted to explore this model. For example, Kaye and colleagues (1982) reported increased endogenous opioid activity in the CSF of severely underweight patients with AN, but not in weight restored or normal controls. Kaye and colleagues (1987) later reported decreased CSF levels of beta-endorphin as well as its three sister peptides, beta-lipotropin, adrenocorticotropic hormone (ACTH), and pro-opiomelanocortin (POMC), in underweight AN patients, suggesting that underweight anorexics have state-associated abnormalities that are part of the neurobiological syndrome of AN and may contribute to alterations in behavior and neuroendocrine function. Brambilla and associates (1995) reported that patients with AN (both AN-R and AN-BP) had significantly higher lymphocyte concentrations of beta-endorphin than in controls. This was especially true for patients with AN-BP. Marrazzi et al. (1997) reported elevated levels of endogenous plasma alkaloids in patients with AN and bulimia nervosa (BN) in comparison to controls. Lesem et al. (1991) did not find significant differences in CSF
levels of dynorphin in patients with AN or BN in comparison to controls. Although there have been no new studies in this century, taken together, the data clearly indicate that the opioid system is dysregulated in AN during the low-weight state and are compatible with the auto-addiction model of AN. Studies using the opiate antagonist naltrexone in the treatment of AN have been mixed, (Marrazzi et al., 1995a; Marrazzi et al., 1995b), but future studies using larger sample sizes are needed.

Results from a more recent fMRI study were interpreted to be in support of the starvation dependence model (Fladung et al., 2010). Patients with AN and healthy controls underwent a functional MRI during evaluation of visual stimuli. Subjects were shown different images consisting of underweight, normal weight, and overweight whole body images and asked to process each image in a self-referring way. Healthy controls had a pleasurable reaction to the normal weight body image (compared with the other two images), while AN patients had a much more pleasurable reaction to the thin body image (compared with the other two images). Given that activation in the ventral striatal reward system was higher during processing of underweight stimuli in the AN patients, the authors concluded that this differential activation toward disease-related stimuli was consistent with theories of starvation dependence. In a sense, the rewarding aspects of being underweight become “hard-wired” and the longer this condition persists, the more adverse weight restoration may become.

CNS Neurotransmitter Changes

The monoamine neurotransmitters, including serotonin (5-HT), dopamine (DA), and norepinephrine (NE), have been investigated during all phases of illness and recovery from AN (active illness, short-term weight recovery, and long-term weight recovery) using a variety of research methodologies. During the low-weight state all central monoamine neurotransmitters and/or their metabolites (5-hydroxyindole acetic acid [5-HIAA], homovanillic acid [HVA], and methylhydroxyphenylglycol [MHPG], respectively), have been reported to be significantly decreased when compared to normal weight healthy controls. Such alterations lead to altered neurotransmitter receptor subtype sensitivity (either upregulation or downregulation) in various brain circuits affecting a variety of psychobiological parameters or functions that are known to be disturbed in AN, for example, hunger, satiety, mood, anxiety, activity, impulsivity, and perception. These results have been considered in detail elsewhere (see Brewerton, 1995; 2002; Brewerton and Steiger, 2004; Brewerton, Frampton & Lask, 2009; Kaye, 2008), but will be reviewed briefly here.

Serotonin

Several avenues of research demonstrate disturbances of serotonin (5-hydroxytryptamine, 5-HT) function in patients with AN. 5-HT is
known to play a major role in the regulation of a number of physiological parameters and behavior that is intimately linked to ED, such as starvation, feeding, satiety, mood, anxiety, harm avoidance, obsessionality, impulsivity, aggression, social behavior, body image, and regulation of hormones and other neurotransmitters. In comparison to healthy controls, underweight patients with AN have been reported to have significantly reduced CSF concentrations of the 5-HT amino acid precursor, L-tryptophan (l-TRP), and the 5-HT metabolite, 5-HIAA. Normalization of these concentrations occurs with short-term weight recovery (goal-weight maintenance > 3 weeks). In direct contrast to the ill state, patients with AN who have achieved weight recovery for more than one year have significantly higher CSF 5-HIAA concentrations than controls (Kaye et al., 1991). These and other data led to the proposal that AN may involve a primary state of excessive serotonergic tone that is consequently counteracted by starvation-induced declines in 5-HT function during the active phase of the disorder and that this purported hyperserotonergic trait may correspond to the personality traits of obsessionality, perfectionism, and behavioral inhibition (Kaye, 2008). Corroborating the notion of hyperserotonergic status in AN, Bailer and colleagues (2007) used positron emission topography (PET) imaging of 5-HT-receptor-specific radioligands and found higher activity of 5-HT1A receptor activity in low-weight patients with AN compared with healthy controls. These investigators also observed that 5-HT2A receptor binding capacity was directly correlated with harm avoidance scores.

Other experiments using serotonergic drug challenges demonstrated impaired serotonergic neuronal function in AN (Brewerton & Jimerson, 1996; Monteleone et al., 1998). Significantly reduced prolactin (PRL) responses following pharmacologic challenges to the serotonin system, using agents such as meta-chlorophenylpiperazine (m-CPP), L-tryptophan (l-TRP) and fenfluramine (FEN), have been described in low-weight patients with AN, further verifying severe changes in serotonin metabolism accompanying this disorder. Following at least one full year of weight recovery, neurohormonal responses following m-CPP normalize in patients with AN. This complete normalization of PRL responsivity to serotonergic agents following weight restoration parallels the stabilization of hypothalamic-pituitary-gonadal function and the cessation of clinically evident ED behavior. Taken together, clinical research findings consistently indicate significantly reduced serotonin synthesis, uptake, and turnover, as well as altered post-synaptic serotonin receptor sensitivity during the active phase of AN. Moreover these changes are likely to be at least partially responsible for the perpetuation of the malignant signs and symptoms characteristic of patients with severe and enduring AN, including severe mood dysregulation, heightened anxiety, relentless obsessionality and compulsivity, marked impulsivity and self-aggression, persistent cognitive distortions, and impediments in learning healthy coping strategies.
Managing Severe and Enduring Anorexia Nervosa

There is considerable evidence for an impaired serotonergic responsiveness during the active phase of AN (Brewerton, 1995; Brewerton & Jimerson, 1996; Monteleone et al., 1998). Studies have shown an inverse relationship between symptom severity and measures of serotonergic responsiveness (Jimerson et al., 1992; Monteleone et al., 2000a). There is also evidence for an association between self-destructiveness, a history of sexual abuse, impulsivity, and reduced serotonin function (Steiger et al., 2001b; Steiger et al., 2001a; Steiger et al., 2001c).

In addition to affecting eating behavior directly, alterations in CNS serotonin function may contribute to other psychological symptoms associated with AN. The diminished CNS serotonin could play a role in the high prevalence of depressive disorders in patients with AN. An impulsive-aggressive behavioral style, which is frequently seen in the binge-purge subtype of AN, may also be associated with diminished CNS serotonin function (Brewerton & Steiger, 2004).

Dopamine

Dopamine (DA) is known to be intimately involved in the hedonic reward responses to eating, feeding, and other pleasurable behavior, which has made it an area of great relevance in AN. Moreover, DA is implicated in the regulation of mood, activity, social behavior, perception, as well as hormone and peptide release (Jimerson et al., 1992). Low-weight patients with AN have been described as having decreased measures of both central and peripheral DA activity, including reduced CSF and plasma concentrations of homovanillic acid (HVA). Although concentrations of CSF HVA have been reported to normalize after long-term recovery, during the active phase of the illness these purported neurotransmitter abnormalities may drive the expression and continuation of symptoms.

Anecdotal reports of the successful use of dopaminergic antagonists (atypical antipsychotic agents), particularly olanzapine, in the treatment of AN patients have been followed by encouraging controlled trials showing olanzapine's efficacy over either placebo or other antipsychotics (Brewerton, 2012).

Norepinephrine

Norepinephrine's (NE's) role in the regulation of eating, mood, anxiety, sympathetic tone, metabolic rate, temperature, and neuroendocrine control has made it a likely focus of study in AN. Low-weight AN patients demonstrate urinary, plasma, and CSF levels of the major metabolite of NE, 3-methoxy-4-hydroxyphenylethanolamine (MHPG). Although these levels completely normalize upon full-weight restoration, low-weight patients with AN tend to have higher plasma NE levels than healthy controls. However, CSF NE levels are reported to be no different
in low-weight AN patients compared with controls and after short-term weight gain. Paradoxically, NE levels become significantly lower after weight recovery of at least six months. The extent to which the adrenergic alterations seen in AN play a role in the perpetuation of symptomatology is unknown. It may be that the profound depletion seen in all monoamine neurotransmitters works in concert to produce impairment and to perpetuate symptomatology.

Neuropeptide and Hormonal Alterations

Patients with AN characteristically have significantly higher plasma cortisol levels in comparison to controls, as well as altered cortisol responses to challenges with ACTH (Brewerton, 1995). Furthermore, plasma cortisol levels have been reported to be inversely correlated to serotonin receptor sensitivity. The stresses of weight loss and chronic starvation, as well as bingeing and purging, may lead to further compromises in serotonergic tone and thereby perpetuate eating and related symptomatology.

Connan and colleagues (2003) have proposed a neurodevelopmental model in which genetic factors and early life experience interact to create vulnerability to a chronic but passive stress response as well as marked hypothalamic–pituitary–adrenal (HPA) axis dysregulation. Psychosocial and biological alterations accompanying puberty intensify vulnerability in such a way that when stress arises, both maladaptive coping and aberrant HPA axis responses are triggered. In particular, the HPA axis does not adjust to the chronicity of the stress, and there is chronically raised corticotrophin releasing hormone (CRH) activity. Chronic elevation of CRH concentrations leads to a long-lasting dysregulation in nutritional homeostasis as well as a host of other effects on brain and body that may contribute to chronicity.

A number of other neuropeptide and hormonal parameters are reported to be significantly different from controls in low-weight AN patients, which may contribute to the perpetuation of the disorder. We have already reviewed evidence regarding alterations in opiates that may reinforce the starvation state and produce a “starvation dependence.”

Altered leptin concentrations have been reported in low-weight AN patients in comparison to matched controls (Baranowska et al., 2001; Brewerton et al., 2000; Jimerson et al., 2000; Monteleone et al., 2000b). Leptin levels appear to remain decreased even after sustained recovery in comparison to controls with matched percent BMI.

There have been consistent reports that plasma ghrelin concentrations are significantly increased in low-weight patients with AN when compared with healthy controls. This increase is more pronounced in patients with AN-BP as compared to patients with AN-R in some but not all studies (Otto, Cuntz & Fruehauf, 2001; Otto, Tschop & Cuntz, 2004; Soriano-Guillen et al., 2004; Tanaka et al., 2003b; Tanaka et al., 2003a; Troisi
et al., 2005; Monteleone et al., 2008). The higher concentrations of ghrelin in underweight AN patients becomes normal with weight recovery, which supports the contention that increased ghrelin release is a state-dependent phenomenon (Janas-Kozik et al., 2007; Otto, Cuntz & Fruehauf, 2001; Otto et al., 2005; Soriano-Guillen et al. 2004; Tanaka et al., 2004).

Genetic Factors

Endophenotype is a term used in psychiatric genetics to describe observable behavioral characteristics that underlie and contribute to certain disease vulnerabilities but are not part of the disorder itself. These characteristics are thought to be heritable, co-segregate with a psychiatric illness, yet exist in the individual regardless of whether or not the illness is active (state-independent). These traits are also found in non-affected family members at rates higher than found in the general population.

Current research has identified several endophenotypes that may contribute to the development and maintenance of AN that are present prior to the onset of the illness and persist after recovery (Bulik et al., 2007). These impairments appear to have a negative influence on ED treatment outcome (Hamsher, Halmi & Benton, 1981; Holliday et al., 2005; Roberts et al., 2007; Szmukler et al., 1992). They include impairments in executive functioning with weak central coherence (“inability to see the forest for the trees,” i.e., imbalance between global and detail processing), and cognitive rigidity with impaired set shifting (inability to shift effortlessly from task to task or to a new life routine, i.e., difficulty adapting to change) (Lopez et al., 2008; Roberts et al., 2007; Tenconi et al., 2010). Perfectionism has also been identified as a potential endophenotype for AN in particular and ED in general (Bachner-Melman et al., 2007). Bulik and colleagues (2007) found that certain aspects of perfectionism (concerns over mistakes and doubts about actions) appear to be significantly associated with both AN and BN but were not associated with any other psychiatric disorder. Tendencies toward excessive motor activity and exercise have been suggested as potential endophenotypes in AN and BN. Studies suggest that physical activity and weight regulation may represent endophenotypes for eating pathology that contribute to etiology (Favaro et al., 2000; Shroff et al., 2006).

Comorbid Psychiatric Disorders

There are several comorbid psychiatric disorders that can maintain the disabling symptoms of SE-AN. In addition to the previously mentioned endophenotypes (i.e., impairment in executive functioning, cognitive rigidity, perfectionism, and excessive motor activity), more than 55% of adult and adolescent patients with AN will have at least one other comorbid psychiatric disorder (Hudson et al., 2007; Swanson et al., 2011).
In addition, approximately a fifth will have a personality disorder (Sansone, Levitt & Sansone, 2006) (see Table 3.1).

Comorbid mood disorders are common in adults with AN (42%) but less common in adolescents (11%), with major depressive disorder (MDD) being the most prevalent in both populations (adult 39%; adolescent 9%) (Hudson et al., 2007; Swanson et al., 2011). One of the major symptoms of MDD is recurrent suicidal ideation, with or without attempts or a specific plan to commit suicide. Rates of suicidal ideation in adolescents with AN are 31%, with 8% reporting at least one suicide attempt (Swanson et al., 2011). Although rates of suicide attempts are higher in patients with BN, the rates of completed suicide are greater in AN (Franko & Keel, 2006), which may be due to the use of more lethal methods (Bulik et al., 2008). Whether mood disorders are present prior to the onset of AN, concurrent with the AN, or the result of engaging in ED behavior (i.e., dietary restraint, weight loss, chronic exercise, purging or other compensatory behavior), they can complicate the treatment and recovery process and can persist even after the amelioration of AN symptoms.

Anxiety disorders (for example, specific phobia, social phobia, obsessive-compulsive disorder [OCD], post-traumatic stress disorder [PTSD], and generalized anxiety disorder) are the most prevalent comorbid psychiatric disorders in AN (adult 48%; adolescent 24%) (Hudson et al., 2007; Swanson et al., 2011). In approximately 75% of cases, anxiety disorders precede the onset of AN (Godart et al., 2000) and often persist after recovery. Anxiety disorders in adolescence, particularly premorbid OCD, increases vulnerability to AN (Buckner, Silgado & Lewinsohn, 2010). Unfortunately, anxiety disorders (particularly social anxiety and panic disorder) tend to be chronic illnesses associated with greater psychiatric and medical comorbidity, higher rates of suicidal ideation and attempts, and substance use disorders (SUDs) (Buckner et al., 2008; Weiller et al., 1996).

Impulse-control disorders (attention-deficit/hyperactive disorder [ADHD], oppositional defiant disorder [ODD], conduct disorder, and intermittent explosive disorder) are present in approximately 30% of adolescents and 31% of adults with AN (Hudson et al., 2007; Swanson et al., 2011). Problems with self-control of emotions and behavioral

| Table 3.1 Lifetime prevalence of psychiatric disorders in anorexia nervosa |
|---------------------------------|-----------------|-----------------|
|                                 | Adults 18–44 (%) | Adolescents 13–18 (%) |
| Mood disorders                  | 42.1            | 10.9            |
| Anxiety disorders               | 47.9            | 23.9            |
| Substance use disorders         | 27.0            | 13.0            |
| Impulse control disorders       | 30.8            | 31.7            |

Notes: 1Adapted from Hudson et al., 2007 (n=2,980); 2Adapted from Swanson et al., 2011 (n=10,123).
Managing Severe and Enduring Anorexia Nervosa

regulation appear to be more common in AN-BP than in AN-R (Ptacek et al., 2010; Yates et al., 2009).

SUDs are prevalent in adults (27%) and adolescents (13%) with AN (Hudson et al., 2007; Swanson et al., 2011). Rates of abuse/dependence vary greatly across AN subtypes, with the AN-BP group reporting a significantly higher incidence of alcohol use disorder (35%) and drug abuse (32%) than the AN-R group (14% and 6% respectively) (Root et al., 2010). SUDs can develop before, during or after the onset of AN, and in some instances, after recovery from AN (Bulik et al., 1997; Strober et al., 1996).

EDs are also comorbid with dissociative disorders (DDs), the presence of which may adversely influence recovery from AN. Dissociative symptoms are commonly encountered in association with PTSD, especially in instances involving severe, early, and chronic childhood maltreatment (Carlier et al., 1996; Chu & Dill, 1990; Chu et al., 1999; Cloitre, Scarvalone, & Difede, 1997; Dancu et al., 1996; Farrington et al., 2002; Nijenhuis et al., 1998; Putnam et al., 1986; Putnam, 1997), but they also occur in the absence of any ostensible PTSD symptoms, which can be masked by the presence of an ED. Higher than expected rates of DDs and symptoms have been reported in individuals with eating disorders or ED symptoms (Abraham & Beaumont, 1984; Demitrack et al., 1990; Gleaves & Eberenz, 1995; Goodwin & Attias, 1993; Everill, Waller & Macdonald, 1995; Levin et al., 1993; Nagata et al., 1999; Meyer & Waller, 1998; Santonastaso et al., 1997; Tobin, Molteni & Elin, 1995; Valdiserri & Kihlstrom, 1995; Vanderlinden et al., 1995; Vanderlinden et al., 1993; Zerbe, 1993). Likewise, higher than expected frequencies of eating disorders and ED behavior has been noted in patients with DDs, especially dissociative identity disorder (DID) (previously called multiple personality disorder) and dissociative amnesia (previously called psychogenic amnesia) (Brewerton et al., 1999; Putnam et al., 1986; Torem, 1986; 1990; 1993). DD symptomatology typically may include depersonalization, derealization, memory alterations (primarily amnesia), identity and time alterations, marked cognitive distortions, somatic sensations, and experiential avoidance.

By definition, AN inherently involves somatic symptoms, for example, altered perception of body size and shape. Links between EDs and somatoform disorders (SDs), now called “somatic symptom and related disorders” in DSM-5 (American Psychiatric Association, 2013), have been reported by a number of investigators (Bienvenu et al., 2000; Grant, Kim & Eckert, 2002; Nijenhuis et al., 1999; Ruffolo et al., 2006). One family study revealed the grouping of OCD with EDs and SDs, particularly body dysmorphic disorder (BDD), which is now classified under “obsessive-compulsive and related disorders” in DSM-5 (American Psychiatric Association, 2013). BDD and EDs are similarly characterized by obsessive and compulsive phenomenology negatively focused on the
body. Other researchers have observed an association between BDD and EDs.

Prior maltreatment or trauma, including childhood sexual abuse (CSA), is a recognized risk factor for SDs (Farley & Patsalides, 2001; Imbierowicz & Egle, 2003; Lieb et al., 2002; Roelofs et al., 2002; Sansone, Gaither & Sansone, 2001) and BDD (Didie et al., 2006). Among women, child maltreatment contributes not only to general somatic preoccupation but to specific somatic symptoms in the throat and chest areas (Sansone et al., 2001), bodily regions typically involved in eating and vomiting. SDs are closely linked to DDs with other psychiatric comorbidity. Measures of somatization and dissociation are significantly and positively correlated with each other (Badura et al., 1997). Somatoform dissociation is a distinct phenomenon commonly seen in individuals with DDs and SDs, and is an important subdivision of ED patients that may contribute to chronicity (Nijenhuis et al., 1999).

The presence of a personality disorder may also contribute to the persistence of AN. The two most common personality disorders found in AN are obsessive-compulsive personality disorder (OCPD) and borderline personality disorder (BPD). Personality disorders, by nature, are enduring ways of viewing and experiencing one’s world that deviate markedly from the expectations of the individual’s culture. These patterns are pervasive and inflexible, ego-syntonic and lead to significant distress and impairment. If personality disorders are not directly addressed in treatment, these symptoms often persist after the elimination of the ED and increase the likelihood of relapse.

OCPD is the most prevalent personality disorder in AN-R (approximately 22%) with a somewhat lower prevalence rate in AN-BP (12%) (Sansone et al., 2006). However, Halmi and colleagues (2005) reported no significant differences across ED subtypes in the prevalence of OCPD and OCD, nor with the association between OCD and OCPD. Specifically, they found OCPD alone in 15% of the AN-R group and 12% of the AN-BP group, and the combination of OCD and OCPD was seen in 16% of the AN-R group and 20% of the AN-BP group. In contrast to OCD, individuals with OCPD have a pervasive preoccupation with orderliness, rules, details, and perfectionism, are devoted to work and productivity, and have a desire for mental and interpersonal control. Halmi and colleagues (2005) also demonstrated that perfectionism scores were highest in those with OCPD, whether alone or in combination with OCD, and concluded that perfectionism seems to be more strongly associated with OCPD symptoms rather than OCD. The pairing of perfectionism with OCPD may be a relevant core behavioral feature underlying vulnerability to ED. Furthermore, Tchanturia et al. (2004) showed that poor performance on set shifting tasks was associated with early childhood OCPD traits, including childhood rigidity and inflexibility. In addition, individuals with anxiety disorders have an increased likelihood of having a personality
disturbance that meets the criteria for OCPD (American Psychiatric Association, 2013). In a systematic review of 11 prospective longitudinal studies and 12 RCT’s, researchers concluded that there is tentative support to suggest that OCPD traits mediate treatment outcome in AN and that AN patients with this personality disorder have a poorer prognosis (Bruce & Steiger, 2005; Crane, Roberts & Treasure, 2007). In a recent 18-year follow-up study of adolescent onset AN, Wentz et al. (2009) found that a poor outcome was forecast by premorbid OCPD, early age at onset, and the presence of autistic spectrum traits. Similarly, in Steinhausen's review (2009) he concluded that features of OCPD contribute to chronicity and hence SE-AN.

BPD is the most prevalent personality disorder in AN-BP (approximately 25%) with prevalence rates of 11% in AN-R (Sansone et al., 2006). Individuals with this personality style experience global dysregulation and have problems in several key areas of functioning, including affect regulation, impulse control, and interpersonal relationships. In addition to EDs, individuals with BPD have high rates of psychiatric comorbidity, including mood disorders, anxiety disorders, SUDs, impulse control disorders and PTSD.

An early study (Johnson, Tobin & Enright, 1989) compared ED patients with and without BPD and found relatively few differences between groups in symptom severity, eating behavior, and attitudes. The only difference found in eating-related behavior at intake was laxative abuse. Eating disordered individuals with BPD endorsed the use and abuse of laxatives as a purging strategy at a clinically-significant higher rate than the non-borderline group. There were, however, striking differences between these two patient populations. The borderline group demonstrated significantly more general psychiatric symptoms, poorer psychosocial adaptation, higher levels of family conflict, and reported significantly higher rates of suicide attempts and engagement in self-injurious behavior. Additionally, the borderline group reported four times as many stressful events associated with the onset of their eating disorder, as did the non-borderline group.

Research suggests that individuals with ED and comorbid BPD have a protracted course of treatment, have a poorer response to treatment, and have higher rates of premature termination from treatment (Bruce & Steiger, 2005). Most researchers suggest that effective treatment with this complex patient group requires an integrated and comprehensive approach that focuses not only on the ED symptoms but also on deficits in the areas of interpersonal skills, affect regulation, and impulse control (Sansone, Fine & Sansone, 1994; Zeeck et al., 2007).

In a major review of outcome studies by Steinhausen (2009), it was concluded that comorbid psychiatric disorders, for example, anxiety disorder, major depression, or substance abuse, have a significantly negative effect on outcome and contribute to the development of SE-AN. Likewise, Steinhausen (2009) noted that BPD symptoms “clearly stand
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out among the unfavorable factors because of a replicated status in various studies.” However, these findings on the prognostic function of comorbid disorders and personality features need further replication (Dennis & Sansone, 2015). Nevertheless, available data and clinical experience suggest that comorbid psychopathology predicts poorer outcome among patients with ED (Davies, Bekker & Roosen, 2011; Keel & Brown, 2010).

Sociocultural and Environmental Factors

Interpersonal Problems

An interrelated issue that can be associated with the maintenance of anorexic symptoms or non-responsiveness to treatment is the failure to resolve or fully process problematic interpersonal issues. Such issues may often intersect or overlap with the negative effects and cognitive distortions discussed elsewhere. Patients with AN are reported to have histories of more problematic social experiences, including histories of family dysfunction and interpersonal stressors that often lead to feelings of low self-esteem, social isolation, lack of perceived support, and poor coping and problem solving skills (Gual et al., 2002; Tiller et al., 1997; Troop et al., 1994). A recent literature review concluded that interpersonal difficulties in patients with AN are related to interpersonal distrust and negative interaction and conflict with others (Arcelus et al., 2013). Schmidt and Treasure (2006) have proposed a cognitive-interpersonal maintenance model of AN and have discussed its implications for research and practice. They emphasized four important and interwoven factors that contribute to chronicity: perfectionism/cognitive rigidity, experiential avoidance, pro-anorectic beliefs, and response of close others. Several researchers have suggested that certain family factors, such as high expressed emotion, misattributions about the illness or unhelpful methods of engaging with the ED symptoms, can affect adherence to treatment or outcome in AN (Eisler et al., 2000; van Furth et al., 1996). These factors are in addition to the various central and peripheral starvation-related maintenance factors of AN that have been discussed previously.

Trauma, Neglect, and PTSD

As previously discussed, individuals with AN are particularly sensitive to stress and adversity. Anorexia nervosa sufferers have significantly higher rates of traumatic experiences and subsequent PTSD or partial PTSD (Mitchell et al., 2012; Reyes-Rodríguez et al., 2011). The literature consistently indicates higher rates of severe trauma and resulting PTSD in those with bulimic symptoms, i.e., bingeing and/or purging (Brewerton, 2014b; in press). Furthermore, the presence of lifetime PTSD or partial PTSD predicts a greater number and severity of comorbid psychiatric disorders which, as
noted elsewhere, likely contribute to SE-AN. Trauma-related disorders, such as BN, AN-BP, major depression, and PTSD, may share common underlying mechanisms that account for such interrelationships, including dysregulation in neuropsychobiological mechanisms that are activated by gene expression and subsequent underlying affective dysregulation, in addition to shared cognitive schemas involving issues of self-esteem, control, guilt, and shame (Brewerton, 2004; 2014). This perspective is supported by several studies of mediating variables between previous abuse and later development of an ED. They demonstrate that impulsivity and fundamental beliefs involving self-esteem, shame, and perceived control are important considerations in understanding etiological mechanisms as well as treatment approaches (Brady et al., 2000; Murray & Waller, 2002; Waller, 1998; Waller et al., 2001; Wonderlich et al., 2001a; Wonderlich et al., 2001b). Rodriguez, Perez & Garcia (2005) reported that the highest likelihood of poor outcome was found in patients with sexual abuse and histories of other violent acts. In addition, this group of patients was at greatest risk for dropout and relapse following treatment. Similarly, Carter et al. (2006) found that patients with AN-BP and a history of CSA were more likely to terminate inpatient treatment prematurely compared to those without CSA. In their study, those with CSA had significantly worse measures of anxiety, depression, obsessive-compulsive symptoms, lower self-esteem, interpersonal problems, as well as eating disorder psychopathology. In a 5-year follow-up study, Vrabel et al. (2010) found that child sexual abuse and avoidant personality disorder interacted together in predicting ED chronicity. Taken together, available studies strongly suggest that severe childhood maltreatment contributes to treatment dropout, chronicity and the development of SE-AN (Brewerton 2004; 2007; Carter et al., 2006; Rodriguez, Perez & Garcia, 2005; Vrabel et al., 2010).

Schmidt et al. (1993) compared the defensive styles of AN and BN patients and healthy female controls in an attempt to establish a link between early childhood adversity and later adult defensive style. Excessive parental control during childhood was a negative predictor of mature defenses and physical abuse a positive predictor of immature defense style. The authors concluded that childhood adversity may constitute a vulnerability factor for the later development of bulimic eating disorders, which is mediated by personality development. In a later study, Schmidt et al. (1997) reported that critical life stresses frequently preceded the onset of AN and BN, and, in particular, problems with sexuality appeared specific in triggering the onset of AN.

**Cultural Effects**

Western culture is a problematic environment for the individual recovering from AN. Pressures to be thin, young, and physically attractive are ubiquitous in modern culture, while a simultaneous exposure to highly
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Palatable and immediately available foods in large quantities makes achieving healthy weight restoration, abstinence from dieting, bingeing and purging and subsequent recovery from AN very difficult. In addition, the existence of overt reinforcements for so-called “thinspiration” and maintenance of weight loss, such as pro-anorexia websites, can be important perpetuating factors to consider (Bardone-Cone & Cass, 2007).

However, Keel & Klump (2003) have argued that AN, unlike BN, is not a Western culture-bound syndrome. They point out that there are several accounts of AN from non-Western cultures, as well as documented examples from medieval times. Investigators have noted that the common denominator in these historical and non-Western cases is that their reasons for weight loss and psychopathology are not based on a thin body ideal or fears about body size or shape. Instead, their food restriction is better explained in terms of religious or ascetic ideals (Schmidt & Treasure, 2006). Furthermore, in an investigation of risk factors for AN, Fairburn et al. (1999) reported that weight- or shape-related criticism by family members had no independent effect on the development of AN. As a result, the cognitive-interpersonal model (Schmidt & Treasure, 2006) does not put emphasis on body size and shape concerns.

Social Reinforcement

Observations from clinical practice indicate that positive reinforcement for weight loss from others may play a powerful reinforcement role in rewarding drive for thinness and weight-loss behavior. Patients often irrationally fear weight gain following cessation of bingeing and purging.

Family Dysfunction

In an important study by Dancyger et al. (2005), the mothers of ED patients were found to rate family functioning as significantly healthier and less chaotic than their daughters. Although there were fewer significant differences between maternal and paternal views of family functioning, there were no significant differences between fathers’ and daughters’ family perceptions. In addition, increased levels of depressive symptoms as reported by the daughters were linked to the perception of high family dysfunction. Differences in viewpoints between parents and daughters regarding family environment may negatively impact on the course of treatment and contribute to the continuation of dysfunctional family patterns.

Adaptive Function

Exploring the adaptive function of a patient’s ED symptoms and behavior can be a very helpful clinical tool. Recognizing the physical, psychological, social, or interpersonal problems that the ED solves or
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governs and pinpointing the secondary gains that ensue from engaging in this behavior can inform the clinician about the predisposing, precipitating, and perpetuating factors that affect the disorder. ED behavior may fulfill an essential function or purpose. It answers a question, solves a problem (apparently), fulfills an unmet need, or modifies the environment in a rewarding way (despite negative consequences). In many cases, the patient does not realize how this behavior is linked to underlying issues. Because these symptoms serve a purpose, they become difficult to relinquish. However, identifying and understanding adaptive function can direct the patient toward acquiring healthier coping strategies and more effective problem-solving methods. In the next section we review, in detail, the adaptive functions that are often found in patients with AN. Exploring the adaptive function can also guide case formulation, treatment team composition, the determination of appropriate level of care, therapeutic modalities, goals of treatment, and treatment approach (Dennis & Helfman, 2010; Dennis, Pryor & Brewerton, 2014).

Common Adaptive Functions Found in Anorexia Nervosa

ED and associated behavior and symptoms are usually much more complicated than simply serving as ways to lose weight or improve one's body image. A variety of psychological problems can be displaced onto food, weight, and shape. Managing food intake and/or expulsion, and hence weight, body size and shape often generates a subjective sense of mastery over a world that is seen as “out-of-control.” Hilde Bruch (1973) wrote that patients with AN have a “profound sense of ineffectiveness,” “lack of awareness of their sensations,” and “feel out of control.” Severe dietary restraint and weight loss is thought to produce a desired outcome, such as offsetting or preventing some life event (for example, parental divorce or college attendance), or decreasing negative affect (for example, anxiety or depression), or enhancing self-esteem, boosting athletic abilities, attracting or avoiding a paramour, reducing sexual desire, or retarding the biological, social, sexual, and psychological challenges of puberty (Arkell & Robinson, 2008; Brewerton, 2004; Costin, 2007; Dennis & Helfman, 2010; Dennis & Sansone, 1989; 1991; 1997; Johnson, Sansone & Chewning, 1992). Other clinical investigators (Persons, 2005; Persons & Tompkins, 2007; Zayfert & Becker, 2007) have also underscored the importance of recognizing the functional links and causative factors between symptoms when developing case formulations and applying evidenced-based therapies for patients with chronic and complex courses.

Managing Maturity Fears

AN most often develops during adolescence, especially as puberty emerges. One of the chief developmental tasks during the teen years is
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**Managing Sexual Conflicts**

Both physical and sexual maturation begin during and continue through adolescence. Increases in the quality and intensity of drive activity, changes in appearance and reproductive capacity, and the sexualization of peer relationships can be tremendous challenges for developing adolescents. Self-induced starvation impedes normal growth and development and sharply reduces gonadal hormone profiles, thereby abolishing libido as well as the secondary sexual characteristics of a mature adult. As previously noted, by seizing control of the body, the adolescent can induce a return to the pre-pubertal psychobiological state where the threat of external sexual attention by peers or internal libidinous drives is reduced or eliminated (Crisp, 1967; 1980; Fornari & Dancyger, 2003; Leon et al., 1985). This particular adaptive function may be manifested in various configurations by patients of all ages with all types of ED. It is especially common for individuals who have suffered childhood sexual abuse or those who have
wrestled with sexual orientation or gender identity conflicts to engage in self-starvation, binge eating and/or purging to cope with sexual issues (Castellini et al., 2013; Ewan, Middleman & Feldmann, 2014).

Providing Structure, Predictability, and Control

The modern world is constantly changing, which requires a high level of adaptation. It can be challenging even for the most adept. It is well known that patients with AN have been reported to manifest cognitive rigidity, anxiety, high harm avoidance, resistance to change, and intolerance of uncertainty (Brewerton, Hand & Bishop, 1993; Holliday et al., 2005). These traits and tendencies are present even after long-term weight restoration, but are much worse during the low-weight, ill state. AN can appear to provide structure and predictability. Dieting and the pursuit of weight loss is a common activity in Westernized cultures that many people participate in, but few are successful. Having a healthy outcome from this endeavor demands commitment, self-sacrifice, and persistence. To attain a sense of control, individuals with AN seize command of their bodies and organize their lives around limiting calories, compulsive rigorous energy expenditure, rejecting previously desired foods, dodging activities that may interfere with their rituals and routines, and formulating a commitment to a long-range, often unrealistic goal. Self-discipline ensures that they do not become selfish or greedy; comfort is found in knowing they will never overindulge (Arkell & Robinson, 2008). For example: “If I exercise for 4 hours every day, eat no more than 500 calories a day, shun any foods that contain fat, and expel anything that is ‘forbidden’ or ‘taboo,’ then I can quickly and effectively achieve my weight loss goals.” This behavior may yield noticeable results, which only reinforces the conviction that “I am strong, in control, and can accomplish something that most individuals can’t.” In a world that seems uncertain, unstable and “out of control,” engaging in anorexic behavior thereby provides a strong sense of safety, mastery, and control.

Consolidating Self-Identity

Another essential but challenging developmental task during adolescence is to solidify a system of personal values, consolidate positive self-esteem, and acquire a stable and integrated self-identity. Adolescents endeavor to be unique individuals even within their own peer groups. AN is a relatively uncommon disorder, girls and women with AN are unique in that they are conspicuous to other people. Their sheer presence among a group of people frequently attracts either attention and concern or admiration. Patients with AN may feel a sense of pride in achieving their weight-loss goals, even if the anorexic behavior compromises physical and emotional health (see Tan, Hope & Stewart, 2003). The glorification of thinness and the glamorization of ED among high-profile celebrities,
musicians, and athletes have contributed to the belief that having an ED is “not so bad.” Unfortunately, they are consolidating a self-identity around a serious and enduring psychiatric illness.

**Escaping, Avoiding, and Numbing**

Patients often engage in ED behavior to modify their current emotional state (Engel et al., 2013; Goldschmidt et al., 2014). Unresolved interpersonal difficulties, problems at school or work, familial discord, teasing or bullying, domestic violence, emotional/sexual/physical abuse, post-traumatic stress disorder or symptoms, all can lead to the use of ED behavior to help individuals anesthetize themselves from negative mood states or to escape unbearable traumatic memories or thoughts or life circumstances. For some individuals, dieting, calorie-counting, exercising, procuring and eliminating food, and maintaining secrecy, becomes highly reinforced chronic behavior that has been conceptualized as addictive in nature (Brewerton, 2014) and which promotes the emergence of refractoriness and the development of SE-AN. They reduce their world to managing hunger and thirst; physical discomfort is often far more acceptable than emotional pain. As noted previously, Vrabel and colleagues (2010) found that avoidant personality disorder and childhood sexual abuse interacted to predict long-term chronicity and therefore SE-AN.

**Punishing the Negative Self**

Eating disorder behavior can be used as a way of inducing self-punishment or dealing with excessive guilt (Berghold & Lock, 2002). This adaptive function is most commonly seen in patients with markedly low self-esteem or histories of childhood maltreatment, as well as those with borderline personality disorder features. This behavior can be employed to reaffirm the patient’s well-established belief that they are not good enough or unlovable, which reinforces their low self-esteem and negative self-concept (for example, “It is my fault what happened to me,” “Bad things only happen to bad people, and they need to be punished”). ED behavior such as severe food restriction (“I am not worthy to eat”), self-induced vomiting (“I need to get all the bad out of me”), chronic use of laxatives (“I deserve to feel pain”), and excessive exercise (“Bad people should suffer”) are often employed and serve as self-punishment. This subgroup of patients frequently exhibits significant dysregulation in numerous areas of their lives (for example, affect, sexual and aggressive impulses, cognitions, interpersonal relationships, and eating and sleep patterns). They may regularly engage in various forms of self-destructive behavior, including polysubstance abuse, or parasuicidal behavior (i.e., cutting, burning, and self-mutilation), other forms of violence, gambling, driving under the influence, sexual promiscuity, shoplifting, and compulsive buying.
This adaptive function is frequently seen in a subgroup of patients that was first identified and described as Multi-Impulsive Bulimia (MIB) by Lacey (1993). This includes a subset of patients that endorses a history of at least three of six impulsive forms of behavior (i.e., severe alcohol abuse, drug abuse, self-harm, suicide attempts, stealing, or sexual promiscuity), has greater overall psychopathology, is likely to have experienced childhood abuse or trauma, and has a poorer outcome than bulimic individuals without high levels of impulsivity (Fichter, Quadflieg & Rief, 1994). As authors, we contend that this clinical profile is also seen in patients with AN, particularly the AN-BP group. MIB has been linked to chronicity (Fichter et al., 1994; Wonderlich et al., 1994).

**Managing Mood Disorders**

There are significantly higher prevalence rates of comorbid mood disorders, such as major depressive disorder, bipolar disorder, and dysthymia in ED patients. Depressive symptoms or mood disorders can either precede (primary mood disorder) or follow (secondary mood disorder) the onset of AN. Wildman, Lilienfeld & Marcus (2004) reported that major depressive disorder preceded the onset of an ED in 33% of their female participants; however, a more recent study found that only 6% of female adolescents with first-onset AN had a premorbid mood disorder (Buhren et al., 2013). Furthermore, AN behavior (i.e., chronic dieting, excessive exercising) can lead to depression, as supported by the classic human semi-starvation study led by Ancel Keys (Keys et al., 1950). In this study, striking changes in emotional states such as elevated levels of depression and anxiety were observed in previously mentally healthy men as dietary limitations and weight loss progressed. As noted elsewhere, major depression is among the comorbid psychiatric disorders that contribute to chronicity. Depression is therefore often a major perpetuating factor in AN and consequently a contributor to SE-AN.

**Reducing Stress and Managing Anxiety**

It has been well established that anxiety disorders, including separation anxiety disorder, social anxiety disorder, post-traumatic stress disorder, obsessive-compulsive disorder, panic disorder, and simple phobias are common comorbid conditions in individuals with AN (Hudson et al., 2007). In the majority of cases, anxiety disorders manifest before the onset of the ED (Deep et al., 1995; Godart et al., 2000; Kaye et al., 2004). As noted previously, patients with AN may be especially susceptible to stress and its many dire effects. The pre-existent presence of anxiety often results in an enhanced sensitivity toward perceived threats, stresses, traumas, or adverse circumstances. This vulnerability has been demonstrated in many ways experimentally. Strober (2004) maintained
that patients with ED have a proclivity to intense fear conditioning, and higher than usual resistance to extinction. McFillin and colleagues (2012) reported that those with ED are more likely to sense aggressive intent in people’s faces in comparison to controls. ED patients also make significantly more facial emotion recognition (FER) mistakes compared to controls. They frequently over interpret fear as anger (Ridout et al., 2012). Other investigators have noted that individuals with AN: (1) typically display high degrees of anxiety sensitivity exemplified by fear of loss of control (Fulton et al., 2012); (2) are usually over-concerned with consequences and show exaggerated inhibition (Kaye, 2008); (3) demonstrate exaggerated anticipatory anxiety (Oberndorfer et al., 2011), and; (4) manifest high punishment sensitivity (Harrison et al., 2010; 2011; Jappe et al., 2011). Other studies reveal AN patients to have impaired flexibility, decreased set-shifting (Roberts et al., 2007; 2010), increased sensitivity to uncertainty (Frank et al., 2012), and weak central coherence (Lopez et al., 2008; 2009). As a consequence, patients are often unable to understand what is important because they give too much attention to the details and are easily overwhelmed by adverse life events and stress.

Case Example

Diane was the oldest of three siblings whose parents divorced when she was seven years old. She was raised by her mother and maternal grandparents in a rural community. From a young age, she was repeatedly sexually abused by her grandfather and forced to watch her younger siblings being sexually abused by him. To insure her silence, her grandfather would give her candy and refrain from abusing her if she did not tell. Her mother worked the afternoon/evening shift and her grandparents were the primary caregivers after school and in the evenings for the children. The grandmother was present but “unseeing.”

Commentary

- Early loss age 7, parents’ divorce.
- Repeated childhood sexual abuse and witnessing violence carries a negative prognosis.
- “Unseeing” responsible adult (emotional neglect).

Diane was exceptionally bright and got a job after school taking care of the horses in order to avoid being home with her grandfather. However, at age 12, she was raped by the stable caretaker. At age 14 she finally revealed the abuse she and her siblings were experiencing but her mother refused to believe her and did not intervene.
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Throughout adolescence she was repeatedly treated at a local hospital for electrolyte imbalances and episodes of fainting due to low weight. She did not achieve a weight that could sustain a menstrual cycle. She never revealed that she was also bingeing on candy and vomiting after all meals. At age 16, she was admitted to the psychiatric unit of her local hospital for AN. She was re-fed to approximately 92% of expected weight and discharged three weeks later. Within two months, she had relapsed but refused further psychological treatment.

**Commentary**
- Being a 12-year-old rape victim by an adult male.
- Problematic disclosure of childhood sexual abuse to a disbelieving mother is a positive predictor of PTSD/dissociation.

At age 18, she attended college but remained significantly under expected weight and engaged in daily binge eating and purging. Her first realization of amnesia or “lost time” happened when she was in college, and periodically reoccurred for the next several years. For example, she realized that she had bought new clothes, found scored exams in her college papers, and had boyfriends (including one of her professors) that she did not remember. She described her college and graduate study years as a time of confidence, productivity, and hypersexuality.

**Commentary**
- Bulimic symptoms in AN carry a negative prognosis.
- Chronic low weight during puberty and adolescence can lead to primary/secondary amenorrhea, osteopenia, and osteoporosis.

**Commentary**
- Severe trauma, including rape and childhood sexual abuse, can cause tremendous emotional and mental disruption and can cause PTSD.
- The trauma may be so overwhelming that the individual may slip into a dissociative state in order to escape and cope.
- Hypersexuality is a common response to sexual abuse, especially during childhood.
Despite her continued eating disorder, she was able to complete an undergraduate degree and a PhD, get married, and start a very successful business in a town away from her family. However, by age 27, she became seriously ill and was admitted to a research hospital for several months for medical stabilization and treatment. Upon completion of her stay, she attended a two-month intensive treatment program, and for the first time revealed her history of rape and repeated childhood sexual abuse to her treatment providers. Her mother and one sibling attended family sessions during her stay, but refused to corroborate her recollections. Upon completion of the intensive program, she was referred for aftercare to an outpatient treatment program in her local community to continue weight restoration and trauma treatment.

**Commentary**

- Repeated disclosure of sexual abuse to disbelieving authorities is a positive predictor of PTSD/dissociative symptoms.
- Repeated intensive treatments that discharge before full weight restoration and the achievement of biological normality increase the likelihood of ED relapse.

For the next nine years she faithfully attended biweekly and weekly therapy sessions, worked on normalizing her eating patterns (with the assistance of a dietitian) and eliminating compensatory behavior, regularly saw her primary care physician to ensure medical stability, and was prescribed an antidepressant to reduce anxiety and depression. Treatment consisted of eating-disorder- and trauma-based CBT and exposure with response prevention. However, treatment was hampered by dissociative episodes, which were brought on by severe anxiety and panic attacks, relaxation and mindfulness exercises, and when confronting traumatic memories. She was unable to reach her target weight range or give up her daily purging.

Her husband actively participated in treatment. He was her business partner, and was devoted to her and her treatment. She was open and candid with him about her abuse and attempted to incorporate him into the treatment process but often sabotaged any of his efforts to assist her in recovery. Additionally, Diane’s mother attended numerous sessions with her but refused to accept her daughter was a victim of childhood sexual abuse.

The toll of AN-BP behavior was significant, including the loss of many of her teeth, bloody vomitus, severe fatigue, hyperacuity to light and sounds, severe osteoporosis, physical weakness, lanugo, significant constipation, severe depression, and chronic anxiety.
Likewise, her marriage suffered as she was unable to be intimate and often stated that she avoided having sex or a menses because she did not want to have children. Her ability to manage stress and the physical challenges of her work were also compromised by her low weight and “forced absences” due to frequent inpatient hospital stays to stabilize her medical condition. She agreed to “medical stabilization” in a hospital setting but repeatedly refused specialized eating disorder treatment at a higher level of care (i.e., inpatient, residential, PHP).

**Commentary**

- **SE-AN leads to a breakdown in every organ system in the body.**
- **Forced into secrecy, ignored by mother and grandmother, and betrayed by a sister who was also abused, can create a double-bind and an extreme sense of abandonment.**
- **SE-AN results in chronically depleted neurotransmitter function, elevated stress hormone levels, and damage to various neuronal circuits involved in attention and memory, emotional regulation, and impulse control.**

In her late 30s, her weight plunged to a BMI of 12.9 and her family and outpatient team “insisted” on specialized inpatient care. Escalating dysphoria, increased dissociative episodes, suicidal ideations, and marital and work-related problems precipitated this decline. During her inpatient stay, she was extremely uncooperative (vomiting daily, repeatedly pulling out her peripherally inserted central catheter [PICC line] and coded twice on the unit and was transported to the emergency room). As her weight declined and her opportunities to purge were curtailed, her dissociative episodes increased. After four months of treatment she was transferred to
an eating disorder inpatient program that also specialized in the treatment of DID. During her final inpatient stay, treatment focused on bringing all of her “alters” together at the table, in order to get her to eat. Against medical advice, she left inpatient treatment but continued outpatient treatment with a DID specialist in her local community. She died of complications of AN-BP at the age of 42.

Diane had a 28-year history of AN-BP brought on by severe childhood sexual abuse, witnessing the abuse of her siblings, and rape as an adolescent. Although she was exposed to cutting-edge interventions at respected treatment facilities, her ability to recover was compromised by authority figures who refused to accept her reality. Her self-sabotaging behavior was indicative of deep-seated internal conflicts and ambivalence about recovery. Her chronic low-weight status interfered with the processing of traumatic memories and her need to avoid this material interfered with her ability to achieve weight recovery. This tragic and fatal case underscores the importance of integrated treatment by a therapist (and treatment team) skilled in both the treatment of severe AN and trauma.

References


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Perpetuating Factors in SE-AN


Chronic and enduring anorexia nervosa (AN) is distinguished by the long-term maintenance of an undernourished or starved state. The recurrent intake of a diet that is inadequate to sustain a healthy weight is the key behavior maintaining this condition. To understand this pathology, we need to understand the brain’s adaptation to starvation and the neural mechanisms that allow or promote the persistent choice of inadequate caloric intake, even when physiology is appropriately signaling starvation and the behavior has clearly become maladaptive and self-destructive. This chapter describes a cognitive neuroscience model of AN that focuses on the persistence of maladaptive behavior. The model aims to examine neural features of restrictive intake and how this may contribute to the chronicity of AN.

The Importance of Dietary Restriction in Chronic Anorexia Nervosa

Eating is a multifaceted behavior, affected by multiple psychological, social, and biological factors. Much is understood regarding appetitive and inhibitory control around normal eating (LaBar et al., 2001; Saper, Chou & Elmquist, 2002; Smeets et al., 2012a), and the value of food as a primary reward at the neurobiological level has been long established (Dagher, 2012; Hassani, Cromwell & Schultz, 2001; Schultz, 1998). Dieting—attempting to restrict intake below caloric needs—is a signature behavior across eating disorders and is associated with disturbances in psychological functioning (Fairburn, 2008). However, in AN, persistent dieting is at its most extreme.

Restrictive caloric intake has been well established and well characterized in AN (Fernstrom et al., 1994; Hetherington & Rolls, 1991; Walsh, 2011). One of the first observational studies of intake among AN demonstrated significantly lower caloric intake compared with healthy peers (Hadigan et al., 2000). Two independent studies of eating behavior demonstrated impressively restricted dietary intake: individuals with AN ate 50–80% less than their healthy peers (Mayer et al., 2012; Sysko et al., 2005).
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These studies further characterized restriction in AN by documenting a specific avoidance of fat intake; calories from fat range from 13–18% in AN, compared to 28–38% among unaffected individuals (Fernstrom et al., 1994; Hadigan et al., 2000; Mayer et al., 2012). The mean duration of illness in these studies was ~eight years, and individuals with both the restricting and the binge-purge subtypes of AN were included, highlighting that, even if binge eating emerges, the core restriction of caloric intake persists. Even after weight restoration and approximately two months of intensive structured treatment, fat intake remained reduced compared with healthy peers (23±9% versus 38±18%, p=0.004), though it improved somewhat (from 18±10%, p=0.04). Systematic assessment of nutrition outside the laboratory has also demonstrated restricted intake (Huse & Lucas, 1984) and echoed the finding of specific avoidance of fat in the diet of individuals with AN (Hadigan et al., 2000). Restrictive eating patterns are related to poor outcome in the longer term. In two separate studies, those individuals whose diets were more restrictive in food variety and energy content were more likely to relapse (Schebendach et al., 2012; Schebendach et al., 2008).

A central problem of severe and enduring AN is that individuals persistently make maladaptive food choices and that this behavior is highly resistant to change. Emotional and cognitive processing have been proposed as important risk and maintenance factors for AN (Haynos & Fruzzetti, 2011; Treasure & Schmidt, 2013). Neurobiological models are developing to explain the entrenched or compulsive nature of this illness (Godier & Park, 2014; Hatch et al., 2010; Marsh, Maia & Peterson, 2009; O’Hara, Campbell & Schmidt, 2015; Steinglass & Walsh, 2006). A critical challenge is to link such models with the brain mechanisms underlying behavior, an important direction made more feasible by advances in cognitive neuroscience.

One emerging hypothesis is that persistent dieting in AN has the behavioral and neural characteristics of “habit” (Walsh, 2013), which have been elucidated through recent neuroscience research. As Walsh describes, restrictive intake in AN is learned, not innate, occurs repeatedly, and, once learned, is elicited by specific stimuli for the individual. Most importantly, once the behavior is established, it takes great effort from the individual to change their dietary choices. As these features are consistent with the behavioral characteristics of habit (Graybiel, 2008; Verplanken & Wood, 2006; Wood & Neal, 2007), it raises questions: Are the neural mechanisms underlying dietary choices consistent with neurobiological models of habits? What neural circuits underlie restrictive dietary intake?

The Neurobiology of Choice and Food Choice

Cognitive neuroscience has made substantial progress in identifying neural mechanisms that underlie decision-making and behavior. Initially,
different brain regions were identified for different types of learning and memory, distinguishing implicit from explicit processes (Doll, Shohamy & Daw, 2015; Poldrack et al., 2001; Shohamy et al., 2009). As behavior is dependent on learning and memory, this led to advances in understanding behavior, and choice behavior specifically (Daw & Shohamy, 2008; Smith & Graybiel, 2013).

An important distinction has been between choices that are goal-directed compared with those that are habitual (Balleine & O’Doherty, 2010; Dolan & Dayan, 2013; Doll et al., 2015). The critical distinction between these two sorts of behavioral control is that goal-directed behavior is defined as that which is driven explicitly by a desired outcome or reward, whereas habitual behavior is defined as relatively insensitive to the desirability of an outcome (Balleine & O’Doherty, 2010). New behavior is typically acquired through goal-directed learning. However, if it is repeated and continues to be reinforced with rewards, at least intermittently, the behavior becomes habitual and relatively insensitive to the receipt of reward and, critically, to any changes in the valuation of the reward; a behavioral shift that is accompanied by a shift in the neural systems supporting behavior (Balleine & O’Doherty, 2010; Daw & Shohamy, 2008; O’Doherty et al., 2004).

In rodents, the key neural substrates have been identified: goal-directed behavior is mediated by the dorsomedial striatum, whereas habitual behavior involves the dorsolateral striatum (White & McDonald, 2002; Yin, Knowlton & Balleine, 2004; Yin et al., 2009; Yin et al., 2005). A variety of experimental tasks have been developed to characterize habitual behavior in humans, revealing a central role for frontostriatal brain regions homologous to those of rodents (Foerde & Shohamy, 2011; Gillan et al., 2011; Knowlton, Mangels & Squire, 1996; Poldrack et al., 2001; Poldrack & Packard, 2003). Specifically, habit learning and habit behavior have been shown to be subserved by the dorsal striatum and associated regions of the frontal cortex (Foerde, Knowlton & Poldrack, 2006; Smith & Graybiel, 2013; Tricomi, Balleine & O’Doherty, 2009; Valentin, Dickinson & O’Doherty, 2007).

These advances largely rest on the study of behavior in healthy individuals, where paradigms for probing reward-driven behavior rely on the use of deliverable rewards, such as money or food. While there are brain regions that encode reward value independent of the type of reward (Bartra, McGuire & Kable, 2013), there are also differences in neural activation depending on the type of reward (i.e. food or money) (Clithero & Rangel, 2013; Levy & Glimcher, 2011; McNamee, Rangel & O’Doherty, 2013). This specificity highlights the importance of studying choice behavior directly around food to understand eating disorders.

Investigation of active food choice is a recent development (Rangel, 2013). A robust literature describing aspects of eating—including taste, appetitive drive, etc.—has demonstrated a role for reward circuitry
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(ventral striatum, anterior cingulate, insula) and limbic regions (hippocampus and amygdala) (Hollmann et al., 2013; Holsen et al., 2005; LaBar et al., 2001; Maffei, Haley & Fontanini, 2012; Smeets et al., 2012b; Van der Laan et al., 2012). Recent studies have looked directly at brain functioning during active food choice using a task in which individuals choose between a range of food items and an individually selected neutral item. Hare and colleagues (Hare, Camerer & Rangel, 2009) demonstrated engagement of the ventromedial prefrontal cortex (vmPFC) during food choice. Individuals who reliably selected the items they had rated as healthy—even when they considered those items not tasty—engaged the dorsolateral prefrontal cortex (dLPFC), presumably to modulate value-related activity in the vmPFC (see Figure 4.1). In one study (Hutcherson et al., 2012), hungry participants were given the opportunity to “bid” for food items and were given different instructions for how to bid on different blocks. In these healthy individuals, the instruction either to “indulge” or “distance” themselves from the choices influenced behavior and neural activity in vmPFC and dLPFC, again suggesting that among healthy individuals both of these PFC regions are involved in value computation and behavior.

Figure 4.1 Brain regions engaged in food choice
In AN, a range of abnormalities in hedonics and reward functioning have been documented (Kaye et al., 2013; Steinglass et al., 2012; Stoner et al., 1996; Wagner et al., 2007). It is therefore necessary to understand neural activity specifically driving food choice, and how these activity patterns relate to actual food choice. For example, it is common to conceptualize restrictive food choice in AN as a manifestation of exceptional control by goal-directed behavior, yet, paradoxically, individuals with AN seem to have limited ability to modify (i.e. control) their restrictive food choice. It may be that pathological maladaptive behavior is mediated by dorsal frontostriatal systems in chronic AN (Steinglass & Walsh, 2006; Walsh, 2013).

What Do We Know About the Neural Mechanisms of Anorexia Nervosa?

Study of the brain in AN has been wide ranging, and has suggested structural, functional, and circuitry differences between AN and healthy peers (Frank et al., 2004; McClelland et al., 2013; Wu et al., 2013). The avenues of research likely to be most relevant to the persistence of maladaptive behavior in AN include the imaging and neurobiological studies that have identified abnormalities in reward processing (Keating et al., 2012; O’Hara et al., 2015; Wu et al., 2013).

In cognitive neuroscience experiments of habit, an experimental paradigm is designed that causes the participant to develop a response under the task conditions, and with manipulations of the task this behavior can be shown to have acquired habit features, i.e. insensitivity to outcome. To understand restrictive intake in AN, we wanted to probe an existing behavior that appears clinically to have become entrenched and difficult to change, like a habit. Therefore, to study AN, we did not need to train participants in a task but rather develop a task to probe an existing behavior to test whether it exhibited characteristics of habits. To do this, we focused on defining inadequate intake as the result of choosing low-calorie, low-fat foods. This creates an experimental model of the behavior of interest. We used a computer task, adapted from Hare (Hare et al., 2009; Hare, Malmaud & Rangel, 2011) to model this choice behavior in AN: The Food Choice Task (Steinglass et al., 2015). The task shows images of food in three blocks. The first two blocks ask participants to rate each food item according to healthiness and tastiness (separate blocks, presented in random order). These blocks provide individual assessments of different foods across two separate value systems, healthiness and tastiness. One food item is selected that has been rated as neutral (by that individual) in both healthiness and tastiness. This becomes the individual’s reference item for making food choices in the next block. In the choice block, individuals choose between the neutrally rated reference food that stays the same on each trial and a series of each of the other food items. The food items in the task range in calories and
fat content. The choice has real consequences as they are administered a snack after the task based on their choices.

We found that individuals with AN make similar choices to their healthy peers when selecting low-fat food; the groups were equally likely to choose the newly presented food over the reference food if it was a low-fat item. The AN group made significantly fewer selections of high-fat foods (Steinglass et al., 2015), behavior consistent with the known eating behavior of individuals with AN (Hadigan et al., 2000; Mayer et al., 2012). In a separate study with the same task, we also demonstrated that for the AN group, caloric intake in a laboratory meal the following day was significantly associated with proportion of high-fat items selected in the task (r=0.61, p<0.01). This demonstrated that behavior on the Food Choice Task reflects real choices and provides a valid measure of a core clinical feature of AN (Foerde et al., 2015).

To begin to examine the neural correlates of food choice, we studied hospitalized individuals with AN (n=21) within two days of admission and compared them with healthy peers (n=21). During fMRI scanning, we administered the Food Choice Task. As expected, the patients with AN were less likely to choose the high-fat food items (Group x Fat Interaction: $F_{1,40}= 32.2$, $p<0.0001$). The strength of preference for each food item was entered on a 5-point scale. We have examined the correlation between blood-oxygenation level dependent (BOLD) signal and each participant’s behavioral choices by entering individual choice ratings in a parametric analysis in order to determine the link between behavior and BOLD activity. Whole brain analyses in HC and AN during food choice showed no significant differences in the vmPFC regions (even at a lenient threshold), but significantly different activation patterns in the dorsal striatum. Region of interest analyses focused on the dorsal striatum, as per the a priori hypothesis. As predicted, in AN, food choices were strongly associated with dorsal striatum activity, a pattern that was not found in HC (Foerde et al., 2015). This replicated previous work showing choice-related activation in the vmPFC (Hare et al., 2009; Hare et al., 2011) and additionally yielded the novel finding that distinct neural systems contribute to food choice in AN relative to HC.

By using experimental methods drawn from cognitive neuroscience, we are able to model real-world behavior that is of great clinical significance and examine its behavioral and neural components. By directly examining neural activity during the core behavior of restrictive food choice, we have identified a potentially important locus of neural circuit abnormality in AN: dorsal striatum. The results indicate that choice behavior in the task is a measure of actual choice behavior related to intake of calories from fat, which, in turn, is related to clinical outcome in AN (Schebendach et al., 2012; Schebendach et al., 2008). The fMRI data suggest that restrictive food choice is related to activity in the dorsal striatum among AN. These findings convincingly suggest a new direction for understanding the persistence of AN.
Healthy individuals make selections by integrating the value of tastiness with the value of healthiness, these two values can be competing. For those who are dieting, food choice often requires prioritizing the healthiness value over the tastiness value. This has been considered a manifestation of “cognitive-control” that is mediated by the prefrontal cortex and the dorsolateral prefrontal cortex (dPFC) in particular. We have begun to test the hypothesis that once dieting has become recurrent—as in the case of AN—the neural control of this decision shifts. The behavior becomes entrenched, and decision-making about food choices is associated by neural activity in the dorsal striatum. As the pathology worsens to become severe and enduring anorexia nervosa, we might expect the brain to show increased habitual control of behavior (see Figure 4.2).

Conclusion

AN is an enigmatic illness, with myriad complex features. The persistent intake of a diet low in calories and low in dietary fat is a central and sustaining feature of the illness. When the illness becomes severe and
enduring, this behavior is likely a key phenomenon as it can maintain and worsen the medical and psychiatric morbidity. Furthermore, the persistence of the starved state may well contribute to the brain changes with effects on neural circuitry that may unfortunately promote the illness. For example, the starved brain may be more prone to utilizing efficient cognitive strategies, such as habit mechanisms. By directly examining food choice in individuals with AN, we have shown that this behavior is mediated by the dorsal striatum, which suggests a potential link with habit neural circuits. These data suggest neural underpinnings of persistent maladaptive choices in AN that are likely related to chronicity of illness. By integrating the perspective of cognitive neuroscience into the study of chronic AN, we can better examine the relationships between brain and behavior in this devastating illness.

References


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5  Treating Severe and Enduring Anorexia Nervosa

A Randomized Controlled Trial

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Randomized controlled trials (RCTs) for anorexia nervosa (AN) are limited and this is especially true for severe and enduring anorexia nervosa (SE-AN) (Wonderlich et al., 2012). There is very limited evidence for the efficacy of any specific approaches from RCTs in adult AN and there have been no RCTs with a primary focus on SE-AN (Hay, Touyz & Sud, 2012; Wonderlich et al., 2012). Such individuals merit research attention as they have the highest mortality rate of any mental illness (Steinhausen, 2002; Harbottle, Birmingham & Sayani, 2008) and they suffer significant medical comorbidity (Arkell & Robinson, 2008; Robinson, 2009; Birmingham & Treasure, 2010; Wonderlich et al., 2012). Patients with SE-AN also have high levels of disability, often being under- or unemployed, supported by health benefit plans, and they can become a significant burden to parents, carers, and health care funders (Treasure et al., 2001; Strober, 2004a; Striegel-Moore et al., 2008).

One of the challenges in tailoring treatment for individuals with SE-AN, is that treatments that focus on both physical and psychological recovery run the risk of misalignment with patient aims and readiness for recovery, which results in high dropout (Wonderlich et al., 2012). Insurance companies often refuse to treat on the basis that these individuals do not...
respond to known treatments and in the United Kingdom, for instance, some National Health Service funders insist that specialist eating disorder services discharge such patients to generic psychiatric services on the same grounds. Globally, treatment programs are limited in their capacity to treat these patients and it has been reported that non-specific medical palliation may become the default care (Strober, 2009; Lopez, Yager & Feinstein, 2010; Kaplan & Buchanan, 2012).

Taking account of these challenges and complexities of treatment, a different paradigm is needed (Goldner, 1989; Yager, 1992; Vitousek, Watson & Wilson, 1998; Robinson 2009; Tierney & Fox 2009; Williams, Dobney & Geller, 2010; Strober, 2004b). Such a paradigm must reflect the severe and enduring nature of this debilitating disorder. Rather than recovery being the basic premise, treatment should focus more upon retention, improved quality of life with harm minimization, and avoidance of further failure experiences (Strober, 2009; Williams et al., 2010). Such an approach needs to take into account the challenges in treating patients with long-standing low levels of motivation for change, neurocognitive deficits, and a self-view and lifestyle dominated by the illness (Strober, 2004b; Schmidt & Treasure, 2006; Hatch et al., 2010; Treasure & Russell, 2011). In the absence of scientific guidelines, clinicians who have the responsibility of treating patients with SE-AN resort to modifying existing treatment protocols, seeking out alternative strategies that make accommodations for patients’ chronic status, paying close attention to comorbidities and blending supportive, harm-reduction and recovery-based strategies (Wonderlich et al., 2012). Wonderlich et al. (2012) state that in the attempt to meet this therapeutic challenge, “treatments may devolve into relatively unfocused, intermittent, supportive interventions, where goals become unclear and monitoring of clinical status becomes impressionistic and imprecise” (p. 476).

Our present study was designed to ascertain whether it is possible to retain patients with SE-AN in treatment and whether clinically meaningful improvement is possible by adapting existing psychotherapy protocols that have demonstrated some efficacy in treating adults with AN. Specifically, the study was designed to test the relative efficacy of a modified cognitive behavioral therapy for AN (CBT-AN) (Pike et al., 2003) that has documented efficacy particularly for relapse prevention for adult AN and a modified specialist supportive clinical management (SSCM) (McIntosh et al., 2006; McIntosh, Jordan & Bulik, 2010), a treatment that has demonstrated utility in two trials in adult AN (McIntosh et al., 2010; Schmidt et al., 2012). Although individuals with SE-AN participated in the initial studies evaluating both CBT-AN and SSCM for adult AN, neither of the previous studies focused exclusively on SE-AN.

Primary outcomes in the current study were quality of life, mood disorder symptoms, and social adjustment. Weight (BMI), eating disorder
psychopathology, motivation for change, and health care burden were secondary outcomes.

Method

Design

Two intervention sites (University of Sydney and St. George’s, University of London) randomized 63 female participants to CBT-AN (Pike et al., 2003), or to SSCM (McIntosh et al., 2006; McIntosh et al., 2010). All participants were aged 18 or older and had met Diagnostic and Statistical Manual of Mental Disorders 4th edition (APA, 2000) criteria for AN, excluding criterion D (amenorrhea), for more than seven years. Previous studies have reported mean duration of illness between five and seven years. Our goal was to address SE-AN, and to be conservative we selected seven years as the lower limit because this was the upper limit of recent adult RCTs (Pike et al., 2003; Walsh et al., 2006; Carter et al., 2009). Individuals whose eating disorder endures for this period of time not only have a long-standing disorder, but also a severe one, which is evident from patient baseline social adjustment, weight, mood, and health status (Strober, 2009). Patients were also included if they met all DSM-IV criteria but presented with a BMI between 17.6 and 18.5. We included patients within this weight range as recent studies comparing full AN with subthreshold AN in adult females showed no differences between these groups (McIntosh et al., 2005; Le Grange et al., 2013).

Randomization was performed by a biostatistician in the Data and Coordinating Centre (DCC) (The University of Chicago), independent from either intervention site. Participants were individually randomized using Ephron’s biased coin approach stratified within sites based on subtype of illness (AN-R vs. AN-BP) and current use of psychiatric medication. Participants were assigned therapists who conducted both forms of treatment to control for non-specific therapist effects. Therapists were three clinical psychologists with extensive experience treating eating disorders in adults. Two 2-day in-person workshops were held to train therapists in manualized CBT-AN and SSCM. The first workshop was held prior to randomization and the second was held one year later. Experts in CBT-AN (Kathleen Pike, PhD) and SSCM (Virginia McIntosh, PhD) were involved in the training of the therapists. Therapists treated pilot cases with each treatment before being assigned randomized cases, and treatment was conducted in clinics for adults with eating disorders at each of the two intervention sites. The Institutional Review Boards of each site approved the study protocol. Weekly multi-site supervision sessions were held to ensure that the therapies were conducted in accordance with the treatment manuals, and that treatment centres retained consistent approaches in terms of clinical and practical decisions. Audio-taped sessions were reviewed by one of the authors (DLG).
Participants

Participants were recruited from July 2007 to November 2010 by advertising to clinicians, clinics treating eating disorders, and on generic websites. After telephone screening (N=159) to determine eligibility, 73 (46%) were invited for in-person assessment (see Figure 5.1). Respective site study coordinators described the protocol in detail to participants.

![Study flowchart](Figure 5.1 Study flowchart)
before written informed consent was obtained and the assessments conducted. Participants were eligible if female (males were excluded as we estimated that the number of such cases would be negligible), 18 years and older, meeting DSM-IV criteria for AN, excluding criterion D (amenorrhea), with an illness duration of at least seven years. Participants were excluded from the study if they presented with a current manic episode or psychosis, current alcohol or substance abuse or dependence, significant current medical or neurological illness (including seizure disorder), with the exception of nutrition-related alterations that impact on weight, were currently engaged in psychotherapy and not willing to suspend such treatment for the duration of their participation in the study, had plans to move beyond commuting distance from the study site in the following 12 months, or did not live within commuting distance to the study site. Eighty-six percent (n=63) of eligible participants agreed to randomization. The majority of those ineligible did not meet DSM-IV weight loss or illness duration criteria.

Treatments

Both treatments involved 30 individual treatment sessions provided over eight months in an outpatient setting. Participants were told that the focus of treatment would be on improving quality of life and that the specific treatment goals would be articulated collaboratively at the outset of therapy.

CBT-AN

The CBT-AN utilized in this trial was based on the CBT-AN protocol developed by Pike and colleagues (Pike et al., 2003) that focuses on the cognitive and behavioral disturbances linked to the core features of AN as well as more global issues associated with AN, including motivational and schema-based work. As originally designed, CBT-AN includes four phases of treatment. Phase I provides specific strategies for initiating treatment, orienting patients to CBT, and addressing issues of motivation. Phase II focuses on strategies for addressing weight gain, addresses cognitive distortions and behavioral disturbances associated with eating and weight. Phase III expands the focus of treatment to schema-based work that addresses relevant issues that extend beyond the specific domain of eating and weight. Phase IV focuses on reviewing the course of therapy, consolidating gains, and preparing to continue the work of CBT-AN independently after therapy ends. Although the four phases of treatment are described sequentially, depending on the course of therapy for each individual, the treatment is flexible in terms of applying modules of the protocol as needed throughout the course of treatment. For the present study, CBT-AN was modified to reflect the shift in treatment goals.
Specifically, weight gain and recovery from core features of the eating disorder was not assumed to be the treatment priority. Instead, treatment goals were set collaboratively and weight gain was encouraged but not identified as the primary goal or focus of therapy (although medical safety was monitored and required to remain in the study). In this study, CBT also allowed greater flexibility in approach and the motivational enhancement section of the manual continued as long as needed.

SSCM

SSCM (McIntosh et al., 2006; McIntosh et al., 2010) combines features of clinical management and supportive psychotherapy. Clinical management includes education, care, and support, while fostering a therapeutic relationship that promotes adherence to treatment. Supportive psychotherapy aims to assist the patient through use of praise, reassurance, and advice. As in the case of CBT-AN, SSCM was modified for this trial, such that weight gain was not prioritized. Instead, SSCM encouraged patients to make changes to improve quality of life and physical well-being. The rationale for this emphasis in treatment is that improvement in domains outside the core pathology can significantly affect patient well-being and disease burden, and research suggests that treatments that target psychosocial functioning are especially appropriate when there has been repeated relapse or long duration of illness. Ultimately, SSCM aims to help individuals improve quality of life, which will further motivate and enable them to make progress on their core eating disorder pathology as well.

CBT-AN and SSCM were both modified to prioritize quality of life and harm minimization associated with the eating disorder, and they both made weight gain a secondary goal. The primary outcome measures were selected to assess at a macro-level the extent to which individuals were better able to find satisfaction in their lives and engage meaningfully with significant others as a result of treatment. The treatments were distinct in that CBT-AN made use of specific cognitive and behavioral strategies, whereas SSCM made use of more general, supportive therapeutic strategies as outlined in the original manuals. Similarities and differences between the two treatments are outlined in Table 5.1.

Assessment and Procedures

Assessment included diagnostic evaluation for weight and eating disorder related symptoms and psychopathology as well as comorbid psychiatric disorders. The patients were assessed at pre-treatment, end of treatment (EOT), 6-month and 12-month follow-up. Independent assessors, blind to treatment assignment, conducted all assessments. With regards to treatment fidelity, all therapy sessions were digitally recorded, de-identified and then forwarded to the Data Management Site for fidelity checking.
Table 5.1 Similarities and differences between SSCM and CBT as modified in this study for treatment of SE-AN

<table>
<thead>
<tr>
<th>CBT</th>
<th>SSCM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients receive motivational enhancement therapy strategies to improve motivation and readiness for change.</td>
<td>Psychoeducational material is given and discussed to increase patient motivation.</td>
</tr>
<tr>
<td>Treatment and sessions are highly structured and largely therapist-directed.</td>
<td>Treatment and sessions are less structured and are based on what the patient brings to the session.</td>
</tr>
<tr>
<td>Eating behavior is directly challenged through use of behavioral experiments and cognitive strategies.</td>
<td>Changes to eating behavior are encouraged using advice and education around nutrition rather than specific strategies.</td>
</tr>
<tr>
<td>Patients are given homework in each session that relates to session content and is always followed up in the next session.</td>
<td>No homework is ever given. Patients may be sent away with educational material, but it is not necessarily raised in the next session.</td>
</tr>
</tbody>
</table>
Secondary Outcome Measures

Body Mass Index (BMI): Weight and height were assessed at baseline, and weight was assessed by the therapist before each therapy session. The participant was weighed in light indoor clothing, without shoes, on a balance beam scale that was regularly re-calibrated. Weight change was calculated in BMI (kg/m²), which allowed us to track treatment course.

The Eating Disorder Examination (EDE) (Fairburn & Cooper, 1993) is a standardized investigator-based interview that measures the severity of the characteristic psychopathology of eating disorders. Studies consistently support its use, sensitivity, reliability, and validity, making it the gold standard for assessing eating disorders.

The Anorexia Nervosa Stages of Change Questionnaire (ANSOCQ) (Rieger, Touyz & Beumont, 2002) is a 20-item multiple choice questionnaire that assesses a patient’s readiness to recover from AN. It has demonstrated good validity and has high levels of inter-rater and test-retest reliability.

Healthcare Utilization: A self-report questionnaire designed specifically for the study with input from health economists, primary care physicians (PCPs), psychiatrists, and medical specialists that assessed the frequency and intensity of the patient’s use of PCP services, eating disorder treatment services, medical services, and specialist appointments over the preceding six-month period.

Participant Safety

Participants were assessed prior to randomization to ensure medical stability for outpatient treatment. During treatment, patients could be referred to their general practitioner who was aware of this RCT and who had consented to follow the patient throughout the duration of this trial. Patients could also be hospitalized for a maximum of 21 days during the course of treatment and still remain in the study upon discharge. An inpatient stay was determined using well-established guidelines as provided by the American Psychiatric Association (APA, 2000) or National Institute for Clinical Excellence (NICE, 2004).

Statistical Analyses

All analyses were conducted using SPSS version 19.0.0. A two-tailed alpha of .05 was used to evaluate all tests of significance. Participants were compared on sociodemographic and clinical characteristics as well as primary and secondary outcome measures at baseline (treatment groups X site), using two-way analysis of variance for continuous measures and logistic regression for dichotomous measures.

All outcome analyses were based upon intent to treat. Missing data for continuous outcome measures at EOT and follow-ups were imputed.
using multiple imputation based upon fully conditional Markov chain Monte Carlo modeling (Schafer, 1997). Data for the final analysis model were based upon the averaged values of 100 separate imputations (Rubin, 2009). Treatment groups were then compared separately at EOT, six-month follow-up, and 12-month follow-up using a general linear model for continuous outcomes, a generalized linear model based upon a negative binomial distribution for count data (i.e., PCP visits, hospital visits), or a logistic regression for dichotomous outcomes (i.e., medication management, medical management). Covariates for all models included baseline observation (with the exception of medication management and medical management), site, AN subtype, and psychotropic medication use. Between-group effect size was calculated using partial eta-squared, which is interpreted as the unique proportion of variance in outcome attributed to treatment group (“small effect” = .01; “medium effect” = .06; “large effect” = .14) (Cohen, 1998). Sensitivity analyses were conducted to evaluate the impact of multiple imputation procedures. The analyses were repeated based upon complete case analysis and imputation based upon last observation carried forward (LOCF) and the results were compared across the three methods. Within-group change from baseline to EOT and follow-up was compared using a repeated measures general linear model. Within-group effect size was based upon the standardized effect size calculated as change from baseline to EOT or follow-up divided by the baseline standard deviation (“small effect” = .20; “medium effect” = .50; “large effect” = .80) (Cohen, 1998).

The primary outcomes were change in measures assessing chronicity, i.e., quality of life, mood disorder symptoms, and social adjustment. Change in weight (BMI), core eating disorder psychopathology, motivation for change, and health care utilization (use of medical services, for example, number of hospital days, PCP and specialist visits), were all secondary outcome measures.

Results

Participant Characteristics

All study participants were female with a mean age of 33.4 years (SD = 9.6, range = 20–62), and mean duration of illness of 16.6 years (SD = 8.5, range = 7–49 years). The mean BMI for the sample was 16.2 (SD = 1.3, range = 11.8–18.5). Nearly three-quarters of participants (n=47, 74.6%) met criteria for AN restricting subtype. In terms of comorbid SCID-I (DSM-IV-TR) (First et al., 2002), Axis I diagnoses, 22 participants (35%) met criteria for a mood disorder or dysthymia, 20 participants (31.7%) met criteria for generalized anxiety disorder, and 16 (25.4%) met criteria for social phobia. Six participants (9.5%) met criteria for obsessive-compulsive disorder, while one participant met
criteria for current substance dependence. Twelve participants in CBT-AN (38.7%) and 14 in SSCM (43.8%) were taking psychotropic medication.

**Randomization and Attrition**

A total of 63 participants were randomized to CBT-AN (n=31) or SSCM (n=32). Table 5.2 presents baseline participant characteristics by group and site. No significant differences on any baseline characteristics were found between treatment groups, sites, or group-by-site interactions.

A total of 55 (87.3%) participants completed treatment, 26 of 31 (83.9%) in CBT-AN and 29 of 32 (90.6%) in SSCM (Fisher’s Exact p = .474). Forty-five (71.4%) participants completed the six-month follow-up (22 CBT-AN, 23 SSCM) and 50 (79.4%) completed the 12-month follow-up (24 CBT-AN, 26 SSCM). In total, 54 (85.7%) participants completed at least one post-treatment assessment (27 CBT-AN, 27 SSCM). There were no significant differences between treatments in follow-up completion rates (p’s = .763–1.00).

Seven patients were admitted to the hospital during outpatient treatment and six were discharged prior to the 21-day maximum stay allowed in this study. One patient required hospitalization for longer than 21 days, refused further treatment, and subsequently died at home during the follow-up phase of this study (this is the death reported in Figure 5.1 at both six- and 12-month follow up for the CBT-AN group). Eleven patients received further treatment, outpatient/partial hospitalization/hospitalization during the follow-up phase of this study. There were no significant differences between treatment groups in terms of hospital visits during treatment (p = 0.417), at 6-month follow-up (p = 0.154), or at 12-month follow-up (p = 0.059).

**Treatment Outcome**

The magnitude and significance of within-group changes on primary and secondary measures of outcome is summarized in Table 5.3. With the exception of the SF-12 Physical Component Scale, both groups experienced significant changes on all primary and secondary measures of outcome at EOT, six-month, and 12-month follow-up. The magnitude of change ranged from moderate (for example, 0.50 for BMI) to large (for example, 1.52 for ANSOCQ). The magnitude of improvements for health-related quality of life, depression, and social adjustment were somewhat larger for SSCM, while those for eating disordered symptom and readiness for change were generally larger for CBT.

Comparisons between treatment groups on outcome measures at baseline (Table 5.4) revealed that SSCM reported higher levels of depression on the BDI ($F_{1,59} = 5.99$, $p = .017$, partial $\eta^2 = .092$) and poorer social adjustment on the WSAS ($F_{1,59} = 4.45$, $p = .039$, partial $\eta^2 = .070$).
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sydney (n=29)</th>
<th>London (n=34)</th>
<th>Total (n=63)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CBT (n=14)</td>
<td>SSCM (n=15)</td>
<td>CBT (n=17)</td>
<td>SSCM (n=17)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, years (mean, SD)</td>
<td>34.3 (11.3)</td>
<td>32.3 (12.1)</td>
<td>34.9 (7.0)</td>
<td>32.2 (8.2)</td>
</tr>
<tr>
<td>Height, cm (mean, SD)</td>
<td>163.6 (5.4)</td>
<td>165.8 (7.6)</td>
<td>167.3 (4.7)</td>
<td>166.0 (5.8)</td>
</tr>
<tr>
<td>Weight, kg (mean, SD)</td>
<td>43.5 (5.9)</td>
<td>44.3 (5.5)</td>
<td>45.9 (3.7)</td>
<td>44.7 (5.5)</td>
</tr>
<tr>
<td>BMI, m/kg² (mean, SD)</td>
<td>16.2 (1.8)</td>
<td>16.1 (1.5)</td>
<td>16.4 (0.9)</td>
<td>16.1 (1.3)</td>
</tr>
<tr>
<td>Duration of illness, years (mean, SD)</td>
<td>15.9 (7.1)</td>
<td>16.4 (11.4)</td>
<td>19.1 (7.7)</td>
<td>14.7 (7.2)</td>
</tr>
<tr>
<td>AN restricting subtype (n, %)</td>
<td>12 (85.7%)</td>
<td>11 (73.3%)</td>
<td>11 (64.7%)</td>
<td>13 (76.5%)</td>
</tr>
<tr>
<td>Never married (n, %)</td>
<td>8 (57.1%)</td>
<td>8 (53.3%)</td>
<td>7 (41.2%)</td>
<td>9 (52.9%)</td>
</tr>
<tr>
<td>Have children (n, %)</td>
<td>4 (28.6%)</td>
<td>2 (13.3%)</td>
<td>3 (17.6%)</td>
<td>4 (23.5%)</td>
</tr>
<tr>
<td>Employed full time (n, %)</td>
<td>4 (28.6%)</td>
<td>4 (26.7%)</td>
<td>8 (47.1%)</td>
<td>9 (52.9%)</td>
</tr>
<tr>
<td>College degree</td>
<td>10 (71.4%)</td>
<td>9 (60.0%)</td>
<td>15 (88.2%)</td>
<td>13 (75.5)</td>
</tr>
<tr>
<td>Current medical concerns (n, %)</td>
<td>13 (92.9%)</td>
<td>12 (80.0%)</td>
<td>15 (88.2%)</td>
<td>14 (82.4%)</td>
</tr>
<tr>
<td>Current psychotropic medication (n, %)</td>
<td>4 (28.6%)</td>
<td>7 (46.7%)</td>
<td>8 (47.1%)</td>
<td>7 (41.2%)</td>
</tr>
</tbody>
</table>
Table 5.3 Within-group changes from baseline by treatment group\textsuperscript{1,2}

<table>
<thead>
<tr>
<th>Primary Outcomes</th>
<th>EOT</th>
<th>6-month follow-up</th>
<th>12-month follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CBT (n=31)</td>
<td>SSCM (n=32)</td>
<td>CBT (n=31)</td>
</tr>
<tr>
<td>EDQOL Total</td>
<td>0.73***</td>
<td>0.92***</td>
<td>0.88***</td>
</tr>
<tr>
<td>SF-12 MCS</td>
<td>0.46*</td>
<td>0.85***</td>
<td>0.43*</td>
</tr>
<tr>
<td>SF-12 PCS</td>
<td>-0.32</td>
<td>0.09</td>
<td>0.09</td>
</tr>
<tr>
<td>BDI Total</td>
<td>0.62**</td>
<td>0.98***</td>
<td>0.70***</td>
</tr>
<tr>
<td>WSAS Total</td>
<td>0.34</td>
<td>0.68***</td>
<td>0.64***</td>
</tr>
<tr>
<td>Secondary Outcomes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMI</td>
<td>0.42*</td>
<td>0.49*</td>
<td>0.24</td>
</tr>
<tr>
<td>EDE Global</td>
<td>0.85***</td>
<td>0.62***</td>
<td>0.84***</td>
</tr>
<tr>
<td>ANSOCQ Total</td>
<td>1.09***</td>
<td>1.46***</td>
<td>1.03***</td>
</tr>
</tbody>
</table>

\textsuperscript{1}Cell entries represent within-group standardized effect size (i.e., change from baseline in baseline standard deviation units). \textsuperscript{2}Positive effect size indicates improvement; negative effect size indicates worsening. *p < .05, **p < .01, ***p < .001. Abbreviations: EDQOL = Eating Disorders Quality of Life, MCS = Mental Component Scale, PCS = Physical Component Scale, BDI = Beck Depression Inventory, WSAS = Weissman Social Adjustment Scale, BMI = Body Mass Index, EDE Global = Eating Disorder Examination Global Score, ANSOCQ = Anorexia Nervosa Stages of Change Questionnaire.

No significant differences were found between treatment groups at EOT on any measure of outcome or health care utilization (Table 5.4). Analysis at six-month follow-up revealed that CBT-AN had significantly better social adjustment on the WSAS (F\textsubscript{1,57} = 4.51, p = .038, partial $\eta^2$ = .073), however, this finding was not confirmed with sensitivity analysis using complete case or LOCF. Comparisons at 12-month follow-up revealed that CBT-AN was associated with lower eating disordered symptoms on the EDE Global (F\textsubscript{1,57} = 8.90, p = .004, partial $\eta^2$ = .135) and higher readiness for recovery on the ANSOCQ (F\textsubscript{1,57} = 6.59, p = .013, partial $\eta^2$ = .104) compared to SSCM. Both findings were confirmed with complete case analysis, but LOCF failed to confirm the difference for ANSOCQ.

Discussion

This study was designed to determine whether it is possible to treat patients with SE-AN and represents the first RCT to examine the relative efficacy of two manualized treatments specifically tailored for this patient population. The results indicate that, with the exception of SF-12 PCS, both treatment groups experienced significant improvements on all primary and secondary outcome measures at all assessment time points and in domains outside the traditional core psychopathology. The magnitude of change ranged from moderate (for example, BMI) to large...
<table>
<thead>
<tr>
<th>Primary Outcomes</th>
<th>Pre-treatment&lt;sup&gt;2&lt;/sup&gt;</th>
<th>EOT&lt;sup&gt;3&lt;/sup&gt;</th>
<th>6-month follow-up&lt;sup&gt;3&lt;/sup&gt;</th>
<th>12-month follow-up&lt;sup&gt;3&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CBT (n=31)</td>
<td>SSCM (n=32)</td>
<td>CBT (n=31)</td>
<td>SSCM (n=32)</td>
</tr>
<tr>
<td>EDQOL Total</td>
<td>1.7 (0.7)</td>
<td>1.9 (0.5)</td>
<td>1.2 (0.8)</td>
<td>1.4 (0.6)</td>
</tr>
<tr>
<td>SF-12 MCS</td>
<td>34.2 (13.2)</td>
<td>29.6 (10.9)</td>
<td>40.2 (11.1)</td>
<td>38.9 (8.9)</td>
</tr>
<tr>
<td>SF-12 PCS</td>
<td>50.9 (8.0)</td>
<td>47.1 (9.7)</td>
<td>48.3 (8.4)</td>
<td>48.0 (10.7)</td>
</tr>
<tr>
<td>BDI Total</td>
<td>22.6 (13.6)</td>
<td>30.2 (13.2)&lt;sup&gt;†&lt;/sup&gt;</td>
<td>14.1 (12.2)</td>
<td>17.2 (12.9)</td>
</tr>
<tr>
<td>WSAS Total</td>
<td>16.0 (10.4)</td>
<td>20.8 (9.3)&lt;sup&gt;†&lt;/sup&gt;</td>
<td>12.4 (9.9)</td>
<td>14.4 (9.2)</td>
</tr>
<tr>
<td>Secondary</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcomes</td>
<td>BMI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16.3 (1.3)</td>
<td>16.1 (1.4)</td>
<td>16.8 (1.5)</td>
<td>16.8 (2.0)</td>
</tr>
<tr>
<td></td>
<td>EDE Global</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3.0 (1.4)</td>
<td>3.0 (1.3)</td>
<td>1.7 (1.1)</td>
<td>2.2 (1.4)</td>
</tr>
<tr>
<td></td>
<td>ANSOCQ Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.5 (0.6)</td>
<td>2.6 (0.5)</td>
<td>3.2 (0.8)</td>
<td>3.4 (0.6)</td>
</tr>
<tr>
<td>Health care</td>
<td>PCP visits</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utilization</td>
<td>2.5 (2.5)</td>
<td>3.3 (3.5)</td>
<td>3.0 (1.9)</td>
<td>3.3 (3.4)</td>
</tr>
<tr>
<td></td>
<td>Hospital visits</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.3 (0.5)</td>
<td>0.6 (1.6)</td>
<td>0.5 (0.7)</td>
<td>0.9 (1.8)</td>
</tr>
<tr>
<td></td>
<td>Medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Management&lt;sup&gt;4&lt;/sup&gt;</td>
<td>3 (9.7%)</td>
<td>6 (18.8%)</td>
<td>3 (9.7%)</td>
<td>5 (15.6%)</td>
</tr>
<tr>
<td></td>
<td>Medical Management&lt;sup&gt;4&lt;/sup&gt;</td>
<td>8 (25.8%)</td>
<td>7 (21.9%)</td>
<td>4 (12.9%)</td>
</tr>
</tbody>
</table>

<sup>1</sup>Cell entries represent unadjusted means (SD) except as noted. <sup>2</sup>Covariates include site. <sup>3</sup>Covariates include baseline score, site, AN subtype and psychotropic medication status. <sup>4</sup>Cell entries represent N (%). Missing data imputed by multiple imputation. Abbreviations: EDQOL = Eating Disorders Quality of Life, MCS = Mental Component Scale, PCS = Physical Component Scale, BDI = Beck Depression Inventory, WSAS = Weissman Social Adjustment Scale, BMI = Body Mass Index, EDE Global = Eating Disorder Examination Global Score, ANSOCQ = Anorexia Nervosa Stages of Change Questionnaire. †SSCM > CBT: p < .05, WSAS partial eta-squared = .073; ‡CBT > SSCM: p < .05, EDE Global eta-squared = .135, ANSOCQ partial eta-squared = .104.
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(for example, ANSOCQ). In particular, the magnitude of improvements in health-related quality of life, depression, and social adjustment were particularly large for SSCM, which is in keeping with the basic tenets of such a treatment.

It is important to note that while there were no significant differences between the two treatment groups at EOT, differences were seen at six- and 12-month follow-up. Those who had received CBT-AN showed better social adjustment as measured by the WSAS at six months, and at 12 months they showed lower eating disordered symptoms on the EDE Global and improved readiness to change on the ANSOCQ. We suggest this is due to the more active and structured nature of CBT-AN that resulted in more clearly articulated increases in social functioning and eating pathology. Although speculative, the specific skills of CBT-AN may have had the effect of empowering participants to make significant gains in these areas.

Taken together, these findings challenge the established paradigm that individuals with an enduring course of AN have little or no motivation to change and are unlikely to respond to conventional psychosocial treatments (Strober, 2009; Wonderlich et al., 2012). Moreover, low dropout rates in this study may be attributed to the fact that therapists worked on areas that the patient deemed important, in particular areas associated with quality of life, which improved engagement and motivation.

Based on our findings, however, we argue that individuals with SE-AN can make significant strides in terms of achieving a higher quality of life and a reduction in eating disorder pathology as well. By widening the treatment goals, focusing on quality of life, and lessening the pressure to achieve weight gain, we were able to engage individuals with SE-AN in treatment, circumvent the “customary” high dropout rates, bring about significant progress and achieve meaningful positive change in their lives. For individuals with SE-AN, we argue that it is more constructive to address eating and weight pathology with this patient group by setting minimum weight thresholds for treatment participation, rather than setting weight gain or weight normalization as the treatment priority. Although nutritional improvement is encouraged, social activities and leisure pursuits with family members and supportive others are re-established, and appropriate medical follow-up is promoted.

Strengths of the study include a retention rate of 85% (which to our knowledge is the highest of any study of adult AN). Prior CBT studies have demonstrated strong retention rates (65–78%) in relapse prevention, however, dropout is often higher in treatment studies for acutely ill patients (usually in the order of 30%) (Dare et al., 2001; Halmi et al., 2005; Bulik et al., 2007; Glasofer et al., 2013), so our ability to retain a strong majority of patients across treatments is especially important. Additional strengths are the two-month follow-up, and an independent data center that monitored recruitment, eligibility, and data quality closely.
Outcome assessment consisted of standardized instruments with assessors blinded to treatment group conducting the interviews. Supervision was conducted on a weekly basis throughout the trial and sessions were recorded for quality control. Treatments were manualized with previously tested therapies (CBT-AN and SSCM), and the modified manuals were pilot tested by study therapists before their use. However, several limitations should also be considered, for example, a follow-up period of 12-months, which might be considered short for such a severe and enduring group of AN patients. Furthermore, as in most studies of adults with AN, the current study was hampered by a modest sample size. Notwithstanding, the sample was sufficient to show differences in outcomes between groups for eating disorders symptoms at follow-up but may have been underpowered to detect differences in other outcomes. Most of the outcome measures were self-report with their inherent shortcomings. In addition, this was an open follow-up and patients were able to seek additional treatment if desired. There were also differences in the primary outcome measures at randomization. This was adjusted for in the analysis. Because assignment to treatment group was based upon randomization, any differences between treatment groups at baseline are due, by definition, solely to chance. As such, using covariates in the analyses to control for these baseline differences completely controls for such confounds. Finally, it would have been desirable to have included a third arm of a “treatment as usual” control group, for example, routine clinical monitoring. Such a group would have controlled for non-specific factors such as time alone. Despite these limitations, this remains the only RCT to date to exclusively recruit AN patients with an illness duration of seven years or more.

Conclusion

This study clearly shows that SE-AN patients do respond to, and benefit from, two specialized treatments when done by clinicians with specialist knowledge of enduring eating disorders. Despite the prevailing pessimism in the published literature of retaining such patients in treatment and follow-up (Strober & Johnson, 2012; Waller, 2012; Glasofer et al., 2013), a retention rate of 85% at follow-up was achieved in our study.

The findings of the current study suggest that CBT-AN was superior in reducing core eating disorder symptoms at follow-up, but that CBT-AN and SSCM both contributed to improvements over time in health-related quality of life, body weight, depression, and motivation to change. The magnitude of these changes ranged from moderate to large. The findings of this study should provide hope for those suffering from SE-AN as well as stimulate interest in the development of new psychosocial treatment approaches.
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Author contributions: Drs. Touyz, Le Grange, Lacey, Hay and Crosby take responsibility for the accuracy of the data and the data analyses.

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Declaration of Interest

None

References


Managing Severe and Enduring Anorexia Nervosa


In the vernacular of today’s neuroscience, “custom” refers to habit, an automaticity acquired through repetitions of mental and behavioral experiences the brain registers as it matures. Habit formation is the mind’s natural instinct: to store memory of stimulus-response-reward associations so day-to-day experience has order and selection. Without custom, Hume correctly understood, there would be no continuity of behavior, no explicit understanding of conscious experience or ability to communicate it.

Much has been asked over the years of the origin of habits (Graybiel, 2008): In precisely what ways do they evolve, encoded in what circuitry, and for what specific developmental purpose? How do these enabling mechanisms go awry? Clearly, owing to genetic variation and differences in learning strategy that accrue from early life experience, certain habit tendencies will prevail over others; moreover, as to their distribution in large populations, there will be extremes, not simply in the prominence of these traits, but also in the intensity of their expressions and their modifiability, and, importantly, in their adaptability; resilience at one end, illness risk at the other. The uniqueness of any single life history, Wilson wrote (1978), is written into development by a “hodgepodge of genetic adaptations” that, in time, express “biases of passion and learning propensities,” epiphenomena of the brain’s neuronal machinery. These propensities, Wilson argued, also drive the social experiments the mind naturally evolves on a larger scale as development unfolds.

Habits and the social experiments that derive from them allow us to infer how an individual’s consciousness ponders the meaning, and “feels” the emotional consequences, of its experience. Human consciousness becomes, in effect, its own enabling mechanism. Depending on how
the shaping process evolves, how the brain’s cortico-limbic machinery animates personal experience and, in doing so, shapes cognitive and socio-emotional expectancies (Panksepp, 1998), there may be constraints. We can hope for one outcome over another, but our capacities are not limitless. The adaptive challenges inherent to psychopathology lay in these extremes: biases and propensities that play out in a life hemmed in by habit actions that are automatic, inflexible, dogmatically expressed in ideas that promise the worst possible outcome a life can assume. Sometimes, contrary to good common sense (so it seems), the sufferer professes a strange obedience to their extremes.

Anorexia nervosa (AN) illustrates the paradox better than most psychiatric disorders. On the face of it, the symptoms are utterly improbable, incomprehensible. Not only are they odd, once formed they are difficult to arrest. But more perplexing is this insistence that, not only does the behavior sustain their “safety” and well-being, it constitutes it. In AN, illness rises to the level of selfhood; it becomes, in effect, a consciousness unto itself. Today, clinicians routinely accept that AN has genetic roots. But understanding that biology is at play doesn’t lessen the appeal of thinness to the patient (nor does it explain it fully). Why would it? People naturally imbue their experience with unique meaning, and there is an element of voluntariness in how AN is expressed. If the line between illness and selfhood is weakly defined in AN, why would we not expect patients to believe that the rewards of illness far outweigh the risk created by pathologically extreme actions? As to why it is harder for some with AN to absorb the reality of its crippling consequences compared to others, whether we can distinguish (soon after illness begins) patients who will recover from those whose illness is too hard-wired to bring under control, these are the questions that highlight the challenge of AN in its severe and enduring form (SE-AN).

As one of us (Strober, 2010) recently lamented, in stark contrast to the rather optimistic accounts of AN of Gull (1874) and Lasegue (1873), only rarely does the illness quickly resolve. Success in reversing the malnourished state is common (Touyz et al., 1984), but scant evidence exists on how to best overcome the relentless, perseverating ruminations centered on food consumption and weight and shape when they drag on. Without a firm evidence-base as guide, the individual therapist/treatment center approaches the challenge by drawing on personal experience and intuition. But opinions diverge, sometimes radically. Should recovery be the goal for such a patient? Or, is the greater wisdom to recast treatment goals (Wonderlich et al., 2012), manage the risk, stabilize at the current level of morbidity, and should this fail, then encourage the patient to accept a higher level of treatment intensity? Beyond the essential clinical questions (maybe because of them) are worrisome facts. Many people with AN never seek treatment (Keski-Rahkonen et al., 2007; Ben-Tovim et al., 2001) and even when they do, poor outcomes result, whether from
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treatments too brief or poorly conceived, or refractoriness to change. In a comprehensive review of 119 studies comprising 5590 patients, with a follow-up period ranging from 1 to 29 years, Steinhausen (2002) found that while a mean of 47% of patients had been judged recovered (range 0–92%) and a further 34% judged improved (range 0–75%), 5% had died and 21% had developed a chronic, unrelenting course (range 0–79%). Surprisingly, attention to this latter subgroup is scant (Hay, Touyz & Sud, 2012; Strober, 2010; Touyz et al., 2013). Only one report has set forth guidelines for managing SE-AN (Hay et al., 2014).

Unsurprisingly, other questions arise: How should “chronicity” be defined? Is it ethically responsible to refuse treating the “resistant” patient? How does one gauge the relative value versus risk of involuntary hospitalization? Are patients with SE-AN competent to refuse care, do they have a moral right to die (Waller, 2012; Goldner, 1989; Yager, 1992; see also Chapter 14). In this chapter we aim to review recent literature on the management of SE-AN, including wisdom gained from our collective experience.

One of us (Strober, 2010, pp. 225–226) described the challenge this way:

AN is not the only psychiatric disorder to bear tragic witness to debilitating and demoralizing consequences of odd, apparently volitional acts whose resistance to change frustrates even the most dedicated clinicians. But what is particularly maddening is how, outside the decisions patients make relating to feeding, the distorted perceptions of weight and shape, even very wasted patients can remain capable of routine mental acts, their general reality sense remains intact, and everyday attitudes are as reasonable as everyone else’s.

Why, then, doesn’t the faculty of reasoning through logical discourse extend to their suffering? Others (Long, Fitzgerald & Hollin, 2012) have commented similarly. Despite feverish pleas to eat more, we are met with “I would rather be dead than fat,” or, as another patient described the misery of a life lost: “I would do it again, as it is better to be thin than fat.” The clinical challenge of AN is that the apprehensions it stokes—in patient, family, therapist—are not easily contained (Strober, 2004). Mortality is high (Sullivan, 1995; Steinhausen, 2002; Arcelus et al., 2011), and when AN endures, the public health, personal, and family burdens are debilitating.

A New Paradigm

Robinson (2009) illustrated the point: on measures of quality of life he showed that patients with SE-AN are equal in impairment to those with severe depressive illness and those with schizophrenia, thus making a strong argument for adopting a rehabilitation model whose elements
would include long-term management centered on crisis intervention and broad-based supportive care. For whom this rehabilitative care is meant is captured in Arkell & Robinson (2008), who delineated the characteristics (as we interpret their writing) as marked interpersonal isolation, emotional constraint, intrapersonal avoidance, hypertrophy of self-control, control, and disavowal of self. As to the vulnerabilities involved, conjecture far outweighs science. Treasure and Russell (2011) cite the debilitative effects on brain structure and function of starvation and stress. Others (Strober, 2010; Kaye, Strober & Jimerson, 2009) suggest the role of extreme affective and cognitive phenotypes (worry and fearfulness, neophobia, regimentation, and marked perseverance), given evidence from descriptive studies (Strober 1991; 2010; Anderluth et al., 2003; Karwantz et al., 2002), strong familial aggregation of anxiety disorders in AN (Strober et al., 2007), and the common occurrence of anxiety disorder in advance of its onset (Godart et al, 2003; Kaye et al., 2004; Bulik et al., 1997; Swinbourne & Touyz, 2007).

**Staging Illness: The Question of Heterogeneity**

AN is commonly described as relatively uniform in its presentation, but for a contrast in feeding behavior: a near universal dietary restraint compared with periodic binge eating or purging. Still, other predictable indicators of heterogeneity require attention. A simple point suffices: the affective and cognitive phenomenology witnessed in a 12-year-old is surely different from that of a 40-year-old (see Maguire et al., 2011). The social context is also different: in the child, a family more easily rally to support their child’s care, accepting the hope of a favorable promise, in the adult, relatives who easily vent pervading skepticism and many betrayals of trust, a compassion that wore thin years ago as pleas for change went unheeded (Strober, 2010).

[I]t is only a matter of time before even the strongest bond to the person chronically ill with AN withers, frayed by years of fury, despair, and resignation, unable to hold firm against the unrelenting defense of ideas for which there is no single shred of truth or evidence. It will come when the family has endured what they consider to be the final, painful offense, when the seductive strand of hope is declared lost to madness forever. It will start as before, how she is now ready to consider her poor health with a more reasoned mind . . . that she truly wishes an end to the misery brought on by her illness. It is not that the wish for change at this particular moment is contrived, or that the dialogue in which sorrow for the agony she has caused is not reflected honestly. But when AN advances to this chronic state . . . no longer will anyone truly care.

*Strober, 2010, pp. 227–228*
Uncertainty and Debate: When is Illness Chronic?

No incontrovertible, empirical data exist to define it, and suggestions that have been extrapolated from follow-up studies and clinical experience have not led easily to consensus (Strober, Freeman & Morrell, 1997; Hay et al., 2012). As Wonderlich et al. (2012) note, there is no algorithm for judging a patient chronically ill, no strong effort to establish a demarcation separating potentially chronic cases from those that will remit. On this point, a Delphi study undertaken in the United Kingdom (Tierney & Fox, 2009) failed to reach agreement on the utility of illness duration or the number of prior unsuccessful treatments as definition criteria.

The Clinical Imperatives

The realization comes soon: treatment modalities that met with success in managing younger patients fall flat with this group; motivation to change is weakly professed, acceptance of even small increases in weight is a pitched battle. Indeed, the patient cautions us: pushing weight gain risks upsetting a fragile balance and strengthening resistance; it would strip them of whatever vestige of self-determination they believe (delusionally) they own; force weight gain and their only option, the retaliation, would be death. The dialectic is a risky proposition that all too often ends badly. It isn’t that the therapist’s conviction—adding weight will lessen the physical, psychological, and social burdens that marginalize the patient’s existence—is unreasonable, it’s unpersuasive. The greater the therapist’s attempt to win the patient over, the more likely the patient is to feel the persuasion amounts to a failed empathy, too little appreciation of how frail their consciousness truly is.

Bearing these points in mind, emphasizing the necessity of a shared perspective, a week-by-week collaboration of aims and goals with emphasis placed on the complexities that will stand in the way, is, we believe, a far better foundation for undertaking the management of the chronically ill patient. Just the same, the new paradigm is a difficult one, and far more so for clinician than sufferer: establishing then maintaining a rapport over content, trivial and superficial, finding discussion points in a life depleted of human contact, enduring hours of mind-numbing, exhausting monotony; this is the reality of SE-AN. Nonetheless, it is through such a paradigm, where the focus is less on arresting symptoms than on engaging the patient in less threatening, but still meaningful, ways that the potential for reducing imminent risk is best established (Hay et al., 2014). The aims are first, to maintain symptom stability, to avoid additional weight loss (by maintaining the current caloric intake) or, if weight is declining, to slowly increase caloric intake to halt the trend, and, to the extent reasonably possible, reduce active medical morbidity. Second, to foster improvement in quality of life. There are imperatives: should the patient’s
medical status worsen or if risk of self-harm is imminent, ethically and legally sanctioned interventions must be undertaken. In this regard, it is important that the patient know from the first session that the concept of duty of care—moments when the therapist will feel obliged to act contrary to the patient’s pleas—takes precedent should risk escalate. This can be a hard fought dialect, not because of how intense the objection can be, but rather the unknown: Will the imposed authority prove beneficial, or damaging? Will the patient abruptly terminate care?

When Treatment is Seen as Coercion

As Carney et al. (2006) discuss, there is no well-defined line at the intersection of law and medicine that determines when, and how, a clinician’s authority breaches the patient’s right to autonomous choice. Often, as noted earlier, the decision is defended even though these inarguably ill patients are judged by advocates as being competent to manage their affairs outside this one encapsulated “slip” of their life (Beumont & Carney, 2003). It’s comparable to the anosognosia that impairs self-awareness in other major mental disorders and neurological disease. Simply put, AN does not presume a defect in decision-making (Giordano, 2005). Moreover, clinicians sometimes forget that even when compromised, adults with psychiatric illness are afforded the legal right to refuse care when judged competent. Even when the standard for involuntary hospitalization is met there are caveats (Touyz & Carney, 2010; see also Strober, 2004). What if the patient refuses to eat? Forced nutrition, through whatever mechanism of delivery? What of the involvement of third parties—judicial reviews, hospital ethics committee deliberations—their intervention can irreparably harm the therapeutic relationship (see Chapter 12 for a more comprehensive review).

An Attempt at Clinical Practice Guidelines for SE-AN

In contrast to guidelines written by the APA (Yager et al., 2006) and NICE (2004), the most recently published practice guidelines (Hay et al., 2014) devote a special section to patients with SE-AN. They adopt the core principles advocated in several publications (Strober, 2004; 2010; Williams, Dobney & Geller, 2010; Wonderlich et al., 2012), and also take into account results from the first randomized controlled trial of patients with SE-AN (Touyz et al., 2013). But guidelines are just that: they are general principles, helpful in guiding the care of some, limited in their relevance to individual patients, depending on how the illness is defended.

Even though AN is sustained by malnutrition and predisposing biological traits, its psychopathology can be likened to an existential cocoon of marginal comforts: reassuring esteem-enhancing successes
that allow avoidance of psychosexual growth through a daily regimen of starvation dieting, exercise, and food- and/or weight-dependent rituals. And so it goes, day after day, quelling fear through unremittingly monotonous routines that nonetheless make life existentially bearable and knowable. Disrupt the routine, and the patient’s sense of safety feels shattered. And it is for this reason that the clinical care required here is vastly different and why anticipating the possibility of treatment failure is a justified premise.

Strober, 2010, p. 232

For these reasons, the guidelines presume an *a priori*, collaboratively established, agreement that includes, when feasible, the endorsement of loved ones. In general respects, the foundation for these essentials are not fundamentally different from other recommended approaches (see Hamburg et al., 1989; Goldner, 1989; Yager, 1992; Vitousek, Watson & Wilson, 1998): a supportive environment; clarity of aims and general parameters to assure at least a modicum of emotional safety. What is unique is the prescribed pace of movement toward achieving these aims: slow, carefully measured, thoughtfully considered before any change is enacted. The main elements (Hay et al., 2014) include:

- A comprehensive assessment, extended in time, to allow for deep understanding of the maintaining factors. Simple, attainable goals implemented in stages.
- A primary focus on global adaptive function. Unless requested by the patient, restoration of a specific minimal body weight (or BMI) should not be mandatory. Given the panic that attends the prospect of refeeding with these patients, the shared understanding is crucial to avoid quick disengagement from care.
- An effort to improve nutrition. Most patients with SE-AN are able to increase their daily caloric intake to 1200 kilocalories without gaining weight because of metabolic adaptations to starvation. These adaptations should be carefully explained, and there should be no reproach if the effort is suddenly aborted. The effort can be reintroduced at a later time, often meeting with greater acceptance.
- A crucial improvement of interpersonal functioning; any action that enhances autonomy and independent action, however trivial it may be in the eyes of others, deserves consideration if it affords pleasure or mastery and engages cognitive function.
- Regularly scheduled monitoring of physical health parameters by a psychologically minded physician. Whatever intervention is deemed necessary, it should be communicated to patient and therapist. Knowing that the SE-AN patient often believes a deceit is being planned, the goal needs to be clearly stated, and repeated often: stabilization of health, the avoidance of further deterioration.
An important point: at times, a medical crisis can be leveraged to encourage increases in nutrition, body weight as well.

- It cannot be overstated how ill-informed family members and loved ones can be, even when the treatment history is extensive. Detailed, comprehensive understanding of the illness in compelling prose often reduces negative expressed emotion and enlists loved ones more effectively in the rendering of supportive care (Strober, 2004).
- Because of the challenges work with this population entails, a skilled, highly-experienced multidisciplinary team and access to supportive care when higher levels of care are needed is invaluable.

Reflecting these guidelines is The Community Outreach Partnership Program (COPP), developed by Williams et al. (2010) for those patients who have responded poorly to more traditional recovery programs. With a focus on enhancing quality of life rather than symptom abatement, the treatment team draws not only from highly specialized, hospital-based clinicians, but also from community-based experts in psychiatric rehabilitation. Moreover, the venues of care are broad, extending beyond home and clinic to any setting deemed relevant by the patient and care provider. Further, bearing on the definitional uncertainty (see also Vitousek et al., 1998)—some cases deemed chronic do remit—COPP is not thought of as palliative care. There are preliminary data to support this. Patients attending COPP had a mean duration of illness of 15 years, but over three years of care there were significant decreases in global distress and feelings of hopelessness, and social relationships were also reported to have improved.

**When the Patient Says, “I’m Leaving”**

As we know, patients with AN cope poorly with change; the anxiety is especially intense in those whose illness has advanced. In this regard, ending treatment is not at all uncommon. Sometimes it’s provoked by a disagreement with goals or strategies, but interpersonal conflict with a member of the team is another stated reason. Treatment is also terminated in fearful anticipation of change, even when the change has potential to benefit the patient. Sometimes, the decision is smart: some treatments do harm. When there are no offending circumstances, sensible discharge instructions and recommendations are essential: ongoing medical oversight, hopefully, a check-in with the therapist or treatment team, a welcome to return. Notwithstanding the inevitable worry that follows in the wake of the decision, a respectful end-of-care discussion sometimes encourages the patient to return. Treatment terminations can also adversely impact team morale and cohesion; it can stoke dissent, provoke hostility at both the patient and team leadership, it leads some to question the time, effort, and expense of the work. Open discussion
and debriefing serves a critically important function at these times (see Chapter 11).

To Hospitalize or Not: An Uneasy Balance

The history of patients with SE-AN is frequently marked by multiple, failed admissions to hospital, often accompanied by traumatizing memories of the interventions imposed (La Puma et al., 2009). The practice guidelines previously described emphasize the crucial importance of first establishing realistic goals of such an admission, determining whether the patient’s expressed motivation suggests that symptom and psychological management is feasible and that the prerequisites for their implementation are in place. As for the basic parameters of medical stabilization, systolic blood pressure above 90mm HG, pulse rate above 50 bpm, normal laboratory values are the common ones (Hay et al., 2014). The necessity of supportive psychological services cannot be overstated, as physicians and nurses are quickly overwhelmed by the incessant questioning of these patients: “What are you doing? Are there calories in my IV—how many?” Also potentially challenging is the mixing of patients with SE-AN with those whose illness is less advanced. Without firm team leadership, a staff skilled in giving the properly nuanced care to each group, the risk of “chaos” in the milieu and dissention within the team is considerable, and this is especially the case in programs with high bed counts.

Without discounting the value of a well-managed inpatient service (each of the authors can offer testimony), it has also been our experience that many very ill patients prosper from extended care delivered in day hospital programs. The setting often has greater appeal to SE-AN patients; in turn, they remain under care longer and thus motivation to increase weight and commit to lifestyle changes, however limited they may be, can, in time, grow stronger (George et al., 2004).

Rethinking “Recovery”

It is an emerging philosophy in mental health delivery (Mountain & Shah, 2008; Roberts & Wolfson, 2004) that has similarly been extended to the management of SE-AN (Dawson, Rhodes & Touyz, 2014a; Touyz et al., 2013). At its core is the idea that recovery is a highly personal journey that hinges on hope, spirituality, building interpersonal connectedness, and fostering a sense of agency and personal responsibility, in concert with targeted symptom reduction and overcoming stigma. The movement has its roots in the consumer/survivor movement, which in contrast to the tradition of defining recovery as the absence of symptoms, focuses instead on patient perceived successful treatment outcomes (Anthony, 1993; Jacobson & Greenley, 2001). It grew initially from the pessimism that enveloped the management of schizophrenia; a belief the diagnosis
was a life sentence, that long-term suffering and a reduced quality of life was inevitable (Andresen, Oades & Caputi, 2003). However, during the 1980s, evidence began to emerge suggesting the course in many was more favorable than once believed (Andresen, Oades & Caputi, 2011). This was soon followed by personal accounts of “recovery” that emphasized these elements (Schrank & Slade 2007; Dawson et al., 2014a).

The consumer movement representing those with AN has argued strongly for the importance of interpersonal connection as a prerequisite for change (see Cockell, Zaitsoff & Gegller, 2004; D’Abundo & Chally, 2004; Hsu, Crisp & Callender, 1992; Redenbach & Lawler, 2003; Tozzi et al., 2003). Hay and Cho (2013) discussed the role played by interpersonal connection and hope in how patients sought more effective management of the illness. Others (Dawson, Rhodes & Touyz, 2014b; Wade, Treasure & Schmidt, 2011) highlight the role of therapist attitudes and beliefs in promoting a patient’s willingness to initiate new relationships and undertake new activities, and McIntosh et al. (2005) have argued that such non-specific factors might enhance self-control and autonomy in patients with SE-AN.

With these points in mind, the lead author and colleagues recently examined the comparative efficacy of cognitive behavioral therapy (CBT) and specialist supportive clinical management (SSCM) in SE-AN (Touyz et al., 2013). Given the long duration of illness without sustained remission in this group, their high levels of disability, low motivation to change, and tendency to end treatment prematurely, the outcomes placed less emphasis on symptom reduction, and existing treatment manuals were amended to prioritize patient-specific goals. Weight gain was promoted, but the primary outcomes focused on improving quality of life. Both treatment arms were successful in promoting change over time, but CBT was somewhat more successful improving social adjustment at end-of-treatment; by the 12-month follow-up, those who received CBT had lower Eating Disorder Examination (EDE) global scores and expressed a higher readiness to recover than those receiving SSCM. Furthermore, achieving a positive therapeutic alliance with the patients proved less difficult than anticipated, and the strength of the alliance did not differ across the two treatment arms (Stiles-Shields et al., 2013). Achieving a strong alliance sooner forecast greater restraint and shape concern, although it did not predict change in other ED domains, in levels of depression, or in weight gain. Even the establishment of a therapeutical alliance later in treatment was predictive not only of treatment outcome but also of follow-up for all the domains that were evaluated, with the notable exception of eating concern at follow-up. Another finding of note was that improvements in quality of life may be dependent on symptom change and weight gain (Bamford et al., 2014). The link between quality of life and symptoms should never be ignored and clinicians would be ill advised to shift their attention entirely away from weight and symptom change in favor of
solely improving quality of life. Regarding prognosis, the predictors of more favorable outcomes included younger age, shorter duration of illness, restricting subtype, being employed, not currently receiving psychotropic medication, and better social adjustment.

Perhaps our greatest surprise was the very low attrition in this, although how problematic attrition is in clinical trials of AN is, perhaps, overstated. A recent systematic review of this question found attrition to average one-third of participants (Abdelbaky, Hay and Touyz, 2013). In short, the conventional wisdom of poor sustainability of treatment alliance in SE-AN requires reconsideration, and that adoption of the recovery model in managing goal setting in this population may offer an advantage over the traditional paradigms.

However, notwithstanding the improvements in health-related quality of life, body weight, depression, and motivation to change, patients were unable to achieve a normal healthy body weight by the end of treatment or a 12-month follow-up (Touyz et al., 2013). Weight gain was modest at best. These data remain sobering. Although it is always possible for patients with SE-AN to improve or even recover from the illness, this is, in reality, rare. SE-AN does remain a devastating illness which continues to provide a therapeutic challenge to those clinicians who have the necessary skills to treat this disorder.

Countertransference

Treating patients with SE-AN requires the right blend of temperament and acumen; the wisdom of Solomon and patience of Job, if you will. It is a lengthy process, beset with endless difficulties; the outcome typically achieves only incremental change. The necessary frame of reference is humility and the conviction that some form of change is possible, despite the odds (Theander, 1992). In this same vein, Hay et al. (2014) caution against mandating that a therapist initiate treatment with such patients. Exposing therapists, especially the less experienced, to the countertransference experience of fear, anxiousness, disinterest—a quick burnout—should not be taken lightly. We know of many who have declared an end to their interest in eating disorders soon after being thrown into the fray.

Strober (2004) described the qualities needed for this work: a professional identity that is not measured in a patient’s progress; a respect for solitude, the ability to sit patiently with a life that thinks little of process, a person who is but a sad footnote, who has given up on knowledge that inspires growth; to be at ease in the face of profound sickness, accepting that rarely will the sessions ring with illuminating conversation, that the hour will instead feel grim, tedious, grinding; skill and non-defensiveness managing countertransference, the not infrequent wish to be free of the patient, hoping they will propose, on their own, that treatment end.
Managing Severe and Enduring Anorexia Nervosa

Through it all, maintaining deep compassion for a life denied its essence, sometimes flirting with death, and a willingness to explore the wounds and deprivations of a life not fully lived.

Palliative Care

It is an unpleasant reality: the unimaginable mourning of a life lost. As we complete this chapter, one of us (MS) watched the final deterioration of a young woman who stubbornly fought against change, even the most trivial, for 15 years. Palliative care is easy to grasp in cases of terminal medical disease, but for AN, the concepts are more conflict ridden. The interested reader is referred to the chapter authored by Kaplan and Miles (Chapter 14) for a thought-provoking discussion.

Conclusion

Treatment of the chronically ill demands awareness of the realized “customs” by which these patients insist they must live: without deviating from routines, without contemplation of alternatives or new possibilities. It requires an understanding of why it is hazardous to ask patients with SE-AN to challenge their routines too soon, too forcefully. It requires an understanding of the deeply entrenched principles of living that evolved from their biology and how intervening developmental unease gave increasing strength to the illness. It requires what we believe should properly be seen as the complement to the psychopathology itself: an ability to infer the misery that has pervaded the patient’s mental life over many years, to give testimony to the constraints the illness imposes, to accept (and acknowledge) that the avoidance patterns that mark their life afford no small measure of personal “safety,” to understand the trade-offs.

We have offered but a brief overview of the clinical challenge. As for the possibility that future study will translate into more creative solutions, one can hope. As for that hope, what is clear at the moment is that the alterations of biology that enable SE-AN, the genetic architecture, the role, in some, of adverse circumstances that impact consciousness and sustain avoidance of growth, physical and emotional, remain little studied.

The work is not exciting. It doesn’t enrich; words such as “inspiring” or “rewarding” don’t apply. But the effort is meaningful. To see the meaning is to know why it is important, and to understand why it is important is to know why there is not a place in this work for overzealousness, or fear (Strober, 2004). Respect for the necessity of the “marginal” comforts that patients with SE-AN routinely seek in their day-to-day life—avoiding change, dampening arousal—is primary and principled. Begrudging the patient, challenging, praising effusively, warning—over and over—of dire consequences to come if eating doesn’t improve and expecting them to accede, hesitancy to speak explicitly about the magnitude of suffering,
each of these instincts risks argument, protest, withdrawal. Intellect—
the patient’s that is—doesn’t necessarily help; sometimes it’s a handicap.
Intellect is a good thing of course, unless it guarantees that your patient’s
ability to argue, debate, and dispute will be the beneficiary. It may seem
antithetical to the sacred principle of treatment motivation, but asking
that a compromise be struck, wanting the patient’s grudging cooperation,
means that the single most important element needed for successful
management of SE-AN is lacking. A further caveat: too many SE-AN
patients in one’s clinical care or stepping in to this work too soon—before
breadth and depth of general clinical skills is attained—is unwise.

In closing, more than “instructions” to navigate the process, the
treatment guidelines described herein should be thought of as clinical
values that map directly on to what we know about the metapsychology
of SE-AN. In the translation we can readily deduce attributes of therapist
temperament that favor acceptance and tolerance of the work, and infer
how the guidelines offer a better guarantee of moving the care of patients
with SE-AN forward with less disruption. Finally, at the very least, they
encourage an awareness that something meaningful can be attained.

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Managing Severe and Enduring Anorexia Nervosa


Managing the Patient with SE-AN


This chapter describes the origins and development of specialist supportive clinical management for severe and enduring anorexia nervosa (SSCM-SE) from SSCM, an integration of clinical management for anorexia nervosa and supportive psychotherapy, its adaptation for chronic illness and the comparability of SSCM and SSCM-SE with other therapies in randomized controlled trials (RCTs). The content and three phase structure of SSCM-SE for individual outpatient care is delineated with reference to specific tools and integral features including the collaborative patient-led stance, psychodynamic formulation, comprehensive psycho-education, agreed goals and target symptom checklist, and utility of the termination phase. The chapter closes with a discussion and reflective comments of putative mechanisms of change of SSCM-SE, in particular its modified goals for improved quality of life over weight regain, its flexible approach, and promotion of patient autonomy.

The Evidence Base for SSCM and SSCM-SE

Specialist supportive clinical management (SSCM) was first developed as a “control” therapy in a small single-center RCT of a 20-week outpatient therapy for anorexia nervosa. In this trial, two specialist therapies based on a cognitive behavioral therapy (CBT) or interpersonal therapy (IPT) model were compared with SSCM (McIntosh et al., 2005), which was originally termed non-specific supportive clinical management (NSCM). Contrary to expectations, SSCM proved superior to both CBT and IPT on a primary outcome of a global rating of anorexia nervosa diagnostic features, SSCM was similar to CBT on most secondary outcomes and was superior to IPT on many secondary outcomes. This gave rise to the question of whether SSCM is a valid “control” therapy or may be a useful active therapy for anorexia nervosa treatment and further research testing SSCM efficacy in larger RCTs (Watson & Bulik, 2013).
Since the McIntosh et al. (2005) study there have been two further RCTs published (Schmidt et al., 2012; 2015) and one RCT completed (Byrne, 2013) in which SSCM was compared to a specialized psychotherapy. Schmidt et al. (2012; 2015) did not find the specialized psychotherapy (Maudsley model for treatment of adults with anorexia nervosa [MANTRA]) superior to SSCM in primary outcomes, including weight regain. In the first smaller preliminary trial (Schmidt et al., 2012), SSCM was superior with regard to a secondary outcome, namely the need for additional inpatient or daypatient care. Both therapies in this trial were conducted over 20 weekly sessions. Schmidt et al. (2015) found there was a participant preference for MANTRA in a larger trial of 142 outpatients where therapy was delivered over 20–30 weekly sessions (according to illness severity). In both of these trials there were four additional follow-up sessions and optional sessions with a dietician or a carer.

In the first published RCT (McIntosh et al., 2005), SSCM was not superior in weight regain, but was superior to other specialized therapies with a more global assessment of psychopathology. The evidence at the time of planning the Touyz et al. (2013) trial supported SSCM as a putative suitable comparator therapy in a trial of severe and enduring (SE) anorexia nervosa where the primary outcome was not weight regain. In this study, SSCM-SE was adapted from SSCM to have a primary focus on achieving relief of the core symptoms of anorexia nervosa, encouraging more normal eating, facilitating some weight gain (weight was monitored), but most important to reduce the impact of the illness on the participant’s quality of life and subsequent use of medical services. This RCT is described in more detail in Chapter 4. The findings did not support the superiority of a specialized therapy, CBT adapted for SE illness (see Chapter 8) over SSCM-SE in primary outcomes at end of treatment or follow-up, although there were some differences in secondary outcomes. This chapter will next describe the constituents and unique features of SSCM-SE and then discuss possible mechanisms of its efficacy.

Origins of SSCM-SE

McIntosh et al. (2006; 2010) have written a full description of SSCM. SSCM is an individual psychological therapy developed for use in the outpatient or ambulatory care setting. In SSCM, therapy consists of two strands that run simultaneously throughout therapy sessions. About half of the time in each session is given to each strand. The first strand, clinical management of the illness, is where the therapist guides the patient towards a gradual resumption of normal eating in order to bring about restoration of normal weight. The second strand is where the therapist provides supportive psychotherapy and invites the patient to disclose any current life issues. These issues may relate directly or indirectly to restrictive eating and low weight, or may be unrelated. The therapist
adopts a role that supports and encourages the patient to make changes in eating and in other areas. Consistent with this, the therapist provides good quality information about food, eating, body shape, weight, and anorexia nervosa, and advice about specific strategies that may be helpful. The overall aim is to foster and maintain a therapeutic relationship between patient and clinician that facilitates the establishment of normal eating.

The concept of clinical management came from observations that there was little difference in efficacy for “good clinical care” when compared to specialized psychotherapies in the treatment of depressive disorders (Elkin et al., 1989; Joyce, 1995). Clinical management encompasses support, care, education, and the formation of a therapeutic relationship. Core or target symptoms of the illness are identified and goals for change are agreed upon. Supportive psychotherapy may have been regarded as the lowly “Cinderella” of psychological treatments, but it is an effective therapy (Budge et al., 2010). It does not require extensive training in therapist skills or techniques that are not found in other therapies for anorexia nervosa. It does, however, require very good non-specific therapeutic skills, as described by Frank (1972), Grencavage & Norcross (1990), and Bootzin & Caspi (2002), most notably the capacity to form a relationship where the patient knows they can trust the therapist with confidence and with whom it is safe to express emotion. It also requires experience of working with people with anorexia nervosa and familiarity with the illness, its natural course, likely effective treatments, and their side-effects.

SSCM-SE Structure and Content

As in all therapies (Frank, 1972), in SSCM-SE there is a rationale for and explanation of the patient’s cause for distress and mechanisms for relieving distress, new information concerning the patient’s problem(s) and alternate ways of dealing with it/them, strengthened expectations of help, and facilitation of success experiences.

1. **Initial phase**
   a. Orientation to SSCM-SE
   b. SSCM-SE psychodynamic formulation
   c. Agreement on target symptoms

2. **Middle phase**
   a. Target symptoms review
   b. Supportive therapy
   c. Weight monitoring

3. **Termination phase and planning**
   a. Closure in the therapeutic relationship
   b. Future goals

*Figure 7.1 Phases of SSCM-SE treatment*
In SSCM-SE therapy moves through three overlapping phases (Figure 7.1). In the first phase of SSCM-SE the focus is on establishing and reviewing target symptoms, agreeing on a goal weight, and providing a personalized dynamic formulation of the illness supported by psycho-education. In the second phase, the twin strands of nutritional education and advice with monitoring of the patient’s physical state and supportive psychotherapy are established. The final phase is “termination” and planning post-therapy.

SSCM-SE does not have explicit strategies for motivational enhancement. Motivation is facilitated through the use of support and encouragement, the provision of psycho-educational materials (see Figure 7.2) and most importantly, a shared understanding of factors likely to impede change. The handouts are comprehensive and extensive. In severe and enduring anorexia nervosa (SE-AN), patients may have received such information before or sought it themselves but it is important to revisit relevant areas and to update with new advances in knowledge. For example, the management of osteopenia is changing with more active intervention (Hay et al., 2014).

In the RCT (Touyz et al., 2013), therapy phases were conducted over 30 weekly sessions: 1–5, 5–27, 27–30. As in many RCTs testing efficacy, the number of sessions was constrained by the demands of scientific rigor and funding. In clinical practice the session number and intensity should reflect patient need. However, all phases including termination are integral

1. What is anorexia nervosa?
   a. Epidemiology
   b. Causes: genetic/familial; sociocultural; personal
2. Effects of dieting and problems related to dieting and severe weight loss
3. Sociocultural influences on eating disorders
4. Ineffectiveness of dieting
5. Ineffectiveness of purging and appetite suppressants
6. The cycle of disordered eating
   a. Theories of biological and genetic contribution to weight status and body shape (set point theory)
   b. Effects of starvation (Keys study; see Box 7.1): eating behaviors, mood, social, sexual, cognitive, physical, exercise/activity
7. Society’s fat phobia
8. Exercise as weight control
9. What are the scales really telling you?
   a. Unreliability of weighing
10. Medical consequences of eating disorders
11. Nutrition and recovery from anorexia nervosa
   a. Good nutrition guidelines including eating for bone health

Figure 7.2 Psycho-educational handout topics in SSCM-SE
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to SSCM-SE and it is anticipated that in clinical practice SSCM-SE would occur over about 12 months with weekly sessions. Session frequency may be reduced during the final phase and follow-up or “booster” sessions may be offered. Some people with long-standing illness will need extended therapy or more intensive treatment, including periods of hospitalization for medical stabilization during or following SSCM-SE.

**Initial Phase**

Assessment is crucial to the first phase and includes confirming the diagnosis and assuring the patient that their problems are understood by the therapist. In SSCM-SE it is important to acknowledge the frustration of “starting again” and emphasize that, although the therapy may resemble past experiences and hope for recovery is not abandoned, the aims of therapy have shifted to reducing the impact of the illness on the individual’s quality of life. A full psychiatric, medical, family and personal history, including an eating disorder symptom review and assessment of current dietary intake, is taken in order to develop an aetiological formulation on a timeline mapping the person’s life. The formulation encompasses predisposing (including genetic), precipitating, and perpetuating (or maintaining) illness or risk factors. Protective factors, or those that promote resiliency, are also explored. The formulation is written or drawn, with patient-specific details added, discussed with the patient and used as a basis for treatment priorities (see Figure 7.3). In SSCM-SE it is essential that reasons for previous treatment failures (and current barriers to treatment) are incorporated into the formulation.

![Figure 7.3 SSCM-SE formulation based on biological, psychological, and social predisposing, precipitating, and maintaining factors.](source)

Source: Used with permission from McIntosh and Jordan (2009).
Psycho-education in this phase is comprehensive and should resonate with the formulation. It is emphasized that anorexia nervosa is an illness with major adverse consequences. Patients should be encouraged to think about their own food likes and dislikes in the context of the nutrition information and what may drive eating behavior as exemplified in the Keys study (1950; see Box 7.1). Good nutrition is described as “variety + regular meal times + enough.” Patients are advised that it is not normal to “eliminate” specific foods from one’s diet. The concept of a “healthy weight range” is presented but without the presumption this is achievable or will be a goal of therapy at this time for this patient.

Box 7.1  The Keys Experiment and How it Helps Understanding in Severe and Enduring Anorexia Nervosa

In the 1950s, Ancel Keys, an American scientist, published an extraordinary study known as the Minnesota Starvation Study. It was conducted in the context of the need for better knowledge about food restriction and refeeding during and after the Second World War, when many people in Europe and Asia had suffered extreme levels of food deprivation (Keys et al., 1950).

Whilst the researchers expected and reported new findings on the physical effects of weight loss, they did not expect to find the marked psychological changes that resonate to this day with people who experience anorexia nervosa. This study is therefore often talked about with people with anorexia nervosa to aid understanding of the physical and psychological effects of starvation how these maintain symptoms.

Who Were the Participants and What Happened To Them?

Thirty-six previously well young men who were conscientious objectors to active military service volunteered. After three months of normal eating they were then subjected to six months of severe food restriction (about half daily energy needs) and then refed over three months. Throughout the experiment their physical state was monitored in detail. Weight loss was marked, on average about a quarter of baseline body weight, with some in a state of extreme underweight. The men experienced severe adverse physical and psychological effects. All had profound and similar changes in eating and other behavior, mood, and well-being. All also struggled during the refeeding phase, when uncontrolled overeating often occurred, and experienced lingering effects of starvation.
Reported physical effects included a decreased need for sleep, feeling light-headed and dizzy, recurrent headaches, noise and light sensitivity, muscle weakness and fatigue, ankle swelling (oedema), hair thinning and loss, cold hands and feet, and a slow heart rate. Despite general fatigue, loss of energy, and slowness, they often also felt aroused and restless. A few even apparently tried to accelerate weight loss with compulsive exercise in order to increase their prescribed level of food intake.

They had disturbing changes in thinking, eating, and other behaviour, mood, and well-being. Along with physical slowing, the young men experienced cognitive slowing with difficulty concentrating and making decisions. Depression was common but variable in intensity and duration. Episodes of self-harm occurred and one participant severed three of his fingers. Other mood changes included increased anxiety, irritability and uncharacteristic aggressive outbursts. Behaviour, such as smoking and gum chewing, became more frequent, probably also to reduce hunger. Previously high-functioning young men began to neglect their personal appearance. While some coped better than others, several participants with severe psychological effects needed to be withdrawn from the experiment.

Furthermore, the volunteers changed in “personality” and social manners. They had all been judged to be psychologically stable, intelligent, well-educated, and personable young men. During the experiment they became socially withdrawn, isolative, humorless, and lost self-confidence. This was exacerbated by the decline in sexual interest that we now know accompanies the suppression of sex steroids in starvation. Thoughts, conversation, activities, both awake and asleep, were dominated by food, cooking, and eating. Eating became slow and deliberate. A “buddy” system was introduced to aid the men to desist from eating and especially binge eating when outside the strict confines of the research site.

**Ethics and Empathy**

What is less often discussed are the ethics of the trial and the relationships between researchers and the volunteers. These are explored in Todd Tucker’s book *The Great Starvation Experiment: Ancel Keys and the Men Who Starved for Science* (2006)

The volunteers took great pride in being able to achieve and cope with the suffering induced by the experiment. Breaking down emotionally and eating outside the diet (one was quoted as having eaten from the garbage can and stealing food) caused strong feelings of guilt. Those who were excluded were intensely ashamed of their
weakness and loss of control over eating. These feelings were reinforced by the use of terms such as “cheater” and the deliberate (and now regarded as unscientific) exclusion of their data from the study. In the refeeding phase they also reported concerns about body changes, the mal-distribution of increased body weight, and perceived fatness.

Like the volunteers, people with anorexia nervosa have a high personal and psychological investment in sustaining severe dietary restriction. This is often accompanied by a sense of achievement not elsewise attainable. They also fear the loss of control that accompanies binge eating. Recovery is slow and continues long after weight regain.

But the men in the study only starved for six months. People with years of anorexia nervosa face the same hardships but to a much greater degree and without the “consolation” that they have contributed to medical science. Without doubt they also have endured un-empathic and critical comments from health care professionals when they have “failed” in refeeding regimes.

For these reasons, it is very important that if you are recovering from long-standing anorexia nervosa that you and the people helping you, both professional and personal, understand that is a long and hard road. Agreeing on goals in therapy that are achievable will help ensure the therapy does not become invalidating. Be assertive in finding therapists who can help you to make changes at your pace and provide you with the emotional support you need to do this.

Patients should be encouraged to reflect on medical and psychological consequences and maintaining factors, including how things might be different for them with reduced levels of illness in order to enhance motivation. The therapist is explicit about the challenges ahead (already well known to the patient with SE-AN) and how they will support the patient in making those changes. Previous invalidating treatment experiences and the psychological harm these may have caused are acknowledged as well as the need to ensure there is no repeat of these.

Following assessment the symptom focus is established, goals of therapy are agreed upon, and an individualized Target Symptom Checklist (see Figure 7.4) determined. Two to five goals are usually set and, although the number may vary, there should never be fewer than two goals. At least one goal should be related to reducing a specific symptom of anorexia nervosa (for example, reduced anxiety about being able to eat in front of others or reduced vomiting) and one improving a more general aspect
of quality of life (for example, keeping a job or having better ways of coping with stress than recurrent self-harm). Often, goals may be separated into mini-goals on a path to attaining a larger goal and may be smaller than in SSCM for acute anorexia nervosa as the aim is for improvement rather than recovery. Having no goals is not an option. For the purpose of setting goals, quality of life is conceptualized across a number of domains: family/
partner relationships, friendships, occupation (employment/education), hobbies/interests, social activities, and financial security. In order to reach these goals the target symptom checklist is designed to provide structure to sessions and ensure that the primary focus on symptoms of anorexia nervosa remains.

**Middle Phase**

In the second, or middle, phase the two parts of therapy form its content: clinical management and supportive psychotherapy. Neither takes precedence and the focus of each session is led by the patient not the therapist. Issues from earlier sessions may or may not be further addressed. In clinical management the therapist will refer to the target symptom checklist in order to review the patient’s general progress. Changes are acknowledged and affirmed by the therapist. There is usually support and encouragement of regular eating and further discussion and clarification of nutritional information provided in the psycho-educational materials. If the patient has kept a record of symptoms or eating this may be brought to the session, or alternately their nutritional intake relying on memory recall discussed. Patients can also be encouraged to have meals and eat with people they live with, provided they are comfortable doing so. A focus on symptoms must be maintained throughout this phase. An example of a session in this phase is found in Box 7.2.

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**Box 7.2 Dialogue of Middle Therapy Session**

Sally is a 26-year-old post-graduate student, living in a shared house where cooking is done individually. This dialogue starts about ten minutes into the session. Sally had arrived a few minutes late and was breathless. After she complained of thirst the therapist fetched a glass of water for Sally from the clinic kitchen. Sally was grateful and explained she was out of breath and thirsty as it was a hot day and she had not been able to find a car park close to the clinic.

Therapist: Well, now shall we talk about your target symptoms for this week?
Sally: Yes, OK, but it hasn’t been a good week for me.
Therapist: In what way?
Sally: (tearfully) I had a row with my Mother and now we are not talking.
Therapist: Perhaps you could tell me more about it?
Sally: Gosh, thanks yes.
[For the next 20 minutes the therapist listens to Sally’s account of the altercation with her mother, which was about her mother’s frustration that Sally refuses to eat at her mother’s house. Her mother accused Sally of being ungrateful for the mother’s financial support.]

Sally: Oh, that feels better—I needed to tell someone about it.
Therapist: So what now do you think?
Sally: Um, well, I guess Mother and I will make it up. I know she cares about me really. It’s her birthday coming up soon and Dad will bake a cake and I’ll go over and somehow eat my piece of the birthday cake.
Therapist: Maybe we could weigh you and talk about your target symptoms now?
Sally: Sure.

[The therapist then weighed Sally and referred to the previously formed list:

- Self-weighing (frequent).
- Normalizing eating (food choices restricted to “healthy” foods).
- Reducing coffee (drinking ten or more espressos daily).
- Improving self-confidence.]

Sally: I managed only to weigh myself once this week.
Therapist: Well done!
Sally: Yes, and it was only because I visited a friend who had bathroom scales. My own scales are still locked in the cupboard.
Therapist: Do you think you can get them out of the house entirely?
Sally: No—not quite there yet!
Therapist: And your eating?
Sally: Well, that’s been quite good too actually—I managed to eat some peanut brownies for the first time in I don’t know how long and have at least two meals a day . . .
Therapist: Good! When did you have the brownies?
Sally: Someone brought them into our small group at college to celebrate the end of term.
Therapist: And the two meals—was that every day?
Sally: Well almost—as you know I get up pretty late and one day I got up too late for lunch even.
Therapist: OK—still it’s in the right direction.
Sally: Yes—I think I’m turning a corner despite what my Mother says . . .
Therapist: Yes, it’s hard sometimes for others to appreciate the progress you are making. Should we also have a look at your coffee use? Last time you had reduced to five espressos a day.
Sally: That’s about the same. This week I’ll try and have a couple of days of four espressos?
Therapist: Sounds good. Is there anything in particular making it harder to reduce at the moment?
Sally: No, not really, I think I just like them and a coffee helps me when I’ve been studying at night with end of term exams. I’ll have a go at substituting my night time coffee with a herbal tea infusion—I like them anyway and I think I’d get to sleep better.
Therapist: That’s a good idea—and the other target symptom—your self-confidence—you were working on some ideas around that?

The final section of this session then closed with a review of several strategies Sally had been engaging in that were helping to improve her confidence levels comprising taking a public speaking course and compiling a “goals achieved” checklist, an idea she had downloaded herself from the internet.

The approach in supportive psychotherapy is to encourage the patient to raise other problems or topics that they wish to. This is usually prompted by an open-ended query, for example, “Tell me about your week.” The therapist should convey a positive regard for the patient and helpful interest in their concerns by attentive listening and utilizing empathic responses (for example, “that would have been tough/distressing”). Change is encouraged and supported with appropriate counselling and advice. Advice is provided not in order to solve the problem for the patient, but to enable the patient to think through solutions to problems, or, as in the saying, attaining “serenity” to know the things that cannot be changed and “wisdom” to know the difference. Unlike dynamic psychotherapy, there is no attempt to provide interpretations or psychological insights, or analyse the dynamics of the therapeutic relationship. Sometimes it will be appropriate to make a direct suggestion, but in the context of chronic illness, the therapist needs to be cognizant that the patient may have heard such advice before.

People are weighed at each session but, unlike SSCM, the weight change and physical state need not be a focus unless the patient is becoming unwell and needing more intensive medical care. In clinical practice, if SSCM-SE is delivered by a non-medical therapist the patient will need to also be attending a physician or family medicine specialist. These medical appointments will usually occur monthly but may need to
be more frequent (see Chapter 11 for an account of issues involved in the decision to admit patients with SE-AN).

Collaboration is fundamental to SSCM-SE and the therapist will remind patients that this is a joint endeavor against the illness. It is appropriate to be overt and use phrases such as “we will do this together” or “we’re working as a team.” In SSCM-SE, patients (and therapists) can have points of therapeutic nihilism. When patients feel therapy is not working, the therapist will highlight any changes and achievements they may have made to date. The therapist can reflect on previously identified barriers to change and may revisit and perhaps modify treatment goals to match the patient’s current level of motivation and capacity for change. Goals may be revised to be smaller, achievable, but meaningful and thereby restore the patient’s sense of self-efficacy and belief in treatment. In order to retain trust and credibility in the treatment, therapists need to remind themselves and patients that the goal is not cure or recovery and goals may be as simple as reduced presentations to the Emergency Room. Therapists may need to manage their emotional responses with regular supervision or peer review in order to respect that the patient’s aspirations may not match their own.

**Termination Phase and Planning**

The final phase of SSCM-SE is termination and closure of the therapeutic relationship. It is important to anticipate and normalize ending issues, such as feelings of sadness and loss. Patients may have a slight relapse in the penultimate session and relative recovery by the time of the last session. For readers interested in learning more about termination, and the active use of this phase in therapy, an excellent account is found in Mann (1980). The termination phase will include reassurance and reiteration of knowledge and skills gained.

In SSCM-SE there is a “future focus” where further change is anticipated, future goals reviewed, and further treatment or treatment options discussed and planned as appropriate. In the RCT of SSCM-SE, older patients with more severe illness and depression may have responded better to CBT (Le Grange et al., 2014) and thus it can be anticipated that some patients treated with SSCM-SE may benefit from further treatment or a shift in focus to a more specialized therapist-led approach. The therapist should be confident in acknowledging gains made and saying goodbye and not “au revoir.” Therapists should also convey faith in the patient’s ability to mature further and avoid conveying any anxiety about separating while some issues remain unresolved.

**Putative Mechanisms of Change in SSCM-SE**

There are key features of SSCM-SE that give it “face validity” and make it attractive to the SE-AN group. These include its flexible approach where
treatment is tailored to the individual patient’s specific needs and that patient autonomy is promoted through a collaborative “goal setting” process. Although strategies can be suggested they are never enforced. There is no “homework” or mandated activities. The patient sets the agenda and both therapist and patient accept that goals need not encompass the concept of a “cure.” Consistent with this there is an increased focus on reassurance, consistency, encouragement, psycho-education, and supportive advice. It was unclear but it is possible that, despite low levels of motivation for weight and symptom recovery, the low attrition found in the RCT (Abdelbaky et al., 2014) was because the focus for change was on quality of life rather than weight restoration. Notwithstanding this, changes in eating disorder symptoms were associated with improvements in quality of life (Bamford et al., 2014) supporting the dual roles of clinical management and supportive psychotherapy in SSCM-SE.

Others have written about changing the focus in care in SE-AN. SSCM-SE includes essential features as described by Strober (2010) and Williams et al. (2010), namely, utilizing supportive psychotherapy, encouraging socialization and building support systems external to health care providers, and “going slow” in initial stages where the emphasis is not weight regain but on establishing a sound therapeutic relationship while ensuring medical safety. Both Strober (2010) and Williams et al. (2010) emphasized the importance of promoting self-esteem and autonomy and tailoring treatment to the patient’s stage of change. Secondary analyses of change in the RCT of SSCM-SE also supported the importance of the role of the therapeutic alliance in early and later phases of therapy (Stiles-Shields et al., 2013).

In addition to these non-specific features of psychotherapy, SSCM-SE also shares some specific features with other effective treatments such as CBT-SE (see Chapter 8). For example, there is thorough provision of psycho-education about the illness, including competent nutritional counseling and advice, shared goals of reducing eating disorder symptoms, normalizing eating behavior with improving quality of life rather than a focus on weight regain as the primary goal of treatment. It is not known how much the efficacy of SSCM-SE is in what is shared with other therapies rather than what is different, and only further studies in larger samples will begin to clarify the putative mechanisms of change as discussed here.

References


8 Cognitive Behavioral Therapy for Severe and Enduring Anorexia Nervosa
Kathleen M. Pike and Marion P. Olmsted

Overview of Cognitive Behavioral Therapy for Severe and Enduring AN

Cognitive behavioral therapy (CBT) is perhaps the most widely evaluated and disseminated psychotherapy for eating disorders. With the strongest evidence base in the treatment of bulimia nervosa, CBT has also proven to be effective in the treatment of binge eating disorder and anorexia nervosa (AN) (American Psychiatric Association, 2006; Watson & Bulik, 2013). One of the significant limitations of the treatment studies examining the efficacy of CBT across eating disorders is that they have excluded individuals with persistent eating pathology, particularly in the case of AN. The rationale for such a strategy has been based on the premise that individuals with severe and enduring eating pathology would be unlikely to respond to treatment, and, therefore, limited resources should be directed to new cases where we have greater evidence of treatment efficacy (Hay, Touyz & Sud, 2012). Unfortunately, until recently, this bias in the field resulted in a failure to develop appropriate treatments for individuals with the most severe and enduring AN (SE-AN), leaving therapists and patients without an evidence base to inform clinical care. There is evidence that CBT is effective in reducing relapse in moderately to severely ill AN patients following weight restoration in hospital. Specialized individual CBT focused on relapse prevention has been shown to be more effective than nutritional counseling (Pike et al., 2003) or treatment as usual (Carter et al., 2009) and was not enhanced by the addition of fluoxetine (Walsh et al., 2006). However, outpatient approaches for individuals who refuse hospitalization or other treatments focused on full weight restoration have received little attention in the past.

The absence of an evidence base to guide treatment for individuals with SE-AN is especially problematic given that at least one-third of individuals who develop AN will have the disorder for more than seven years (Steinhausen, 2002). As the eating disorder endures, the risk of associated medical complications and mortality increase as well. Mortality associated with AN is estimated to be approximately 5% per decade (Sullivan, 1995), which is one of the highest rates for all mental health conditions. Medical
complications associated with SE-AN account for approximately 50% of deaths; suicide accounts for approximately 25%; other causes account for the remaining 25%. With this degree of morbidity and mortality, focusing on reducing the deleterious associated effects of the eating disorder has the potential to dramatically enhance quality of life, which in turn has the potential to catalyze efforts to achieve even greater recovery.

A recent study has begun to address this gap in the field. Focused on individuals who had AN for at least seven years, Touyz and colleagues (2013) conducted a study that comprised a total of 63 individuals, 31 of whom received CBT for SE-AN, which is described in this chapter, and 32 of whom received specialist supported clinical management (SSCM, formerly NSCM; see Chapter 7). In contrast to the CBT-AN and SSCM treatments that typically focus on eating disorders symptom reduction and recovery, both psychotherapies were adapted to prioritize harm reduction and quality of life variables as compared to elimination of specific eating pathology.

The primary outcomes of the Touyz et al. (2013) study for SE-AN were quality of life, mood disorder symptoms, and social adjustment. The more specific dimensions of weight, eating disorder psychopathology, motivation to change, and health care burden were evaluated as secondary outcome measures (Touyz et al., 2013). The findings from this study indicated that individuals with SE-AN could benefit enormously from psychotherapy, particularly when the focus shifted away from recovery defined as elimination of eating disorder symptoms to a definition of improved quality of life as promoted from a harm reduction model. It is particularly notable that 85% of patients in the study remained in treatment until the end as compared to typical attrition rates, which hover around 50% for acute care. Moreover, participants in both treatment groups improved significantly and equivalently at the end of treatment. In terms of longer-term outcome, at six-month follow-up, CBT participants evidenced greater social adjustment based on the Weissman Social Adjustment Scale (WSAS), and at 12-month follow-up, they had lower global scores on the Eating Disorder Examination (EDE) than subjects who received SSCM. These results suggest that adapting treatment goals to focus on quality of life and harm reduction for individuals who have SE-AN may ultimately be of greater benefit than treatments that define recovery based exclusively on weight restoration and elimination of eating pathology. This chapter describes in depth the adaptation of CBT for SE-AN that was implemented and evaluated in the Touyz et al. study (2013).

Guiding Principles of CBT for SE-AN

Background and Adaption for SE-AN

CBT for SE-AN builds on earlier CBT approaches and therapists should be well versed in these treatment programs and principles (Pike, Devlin, &
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Loeb, 2003). The more general CBT principles that form the foundation for CBT for eating disorders are based on Beck’s pivotal works in the field (for example, Beck, 1976; Beck et al., 1979) as well as subsequent work by Marlatt and Gordon (1985). CBT manuals and approaches have been designed for bulimia nervosa (Fairburn, 1985; Fairburn, Marcus & Wilson, 1993), for AN treatment and relapse prevention (Garner, Vitousek & Pike, 1997; Pike, Carter & Olmsted, 2006; 2010), and more recently for a transdiagnostic approach (Fairburn, 2008). Therapists should also be familiar with motivational assessment and enhancement strategies (Miller & Rollnick, 1991; Vitousek, Watson & Wilson, 1998), schema-based cognitive therapy (Vitousek & Hollon, 1990; Young, 1990), and cognitive therapy focused on interpersonal processes as described by Safran & Segal (1990).

The recognition that available treatments for AN have limited success and that the illness runs a chronic course for a significant portion of individuals has led to rethinking therapy priorities and goals for individuals with SE-AN. Whereas traditional CBT prioritizes treatment goals that are focused on the elimination of eating disorder symptoms and return to normal functioning, the treatment intervention described in this chapter is informed by a “recovery” model that shifts the focus and goals of treatment. The “recovery” model grew from the recognition that individuals with psychotic illness may lead full and rewarding lives while continuing to have symptoms of mental illness (Dawson, Rhodes & Touyz, 2014). Hope, empowerment, personal control, purpose and meaning in life, quality of life, and symptom management are emphasized in this paradigm (Dawson et al., 2014). The harm reduction approach, elaborated by Marlatt (1998), involves meeting patients where they are and focusing on a non-judgmental analysis of behavior and consequences. The aim is to support any steps to reduce harm that the individual feels capable of making. This approach is not palliative and does not preclude future engagement in treatment that targets the elimination of symptoms. The recovery model and the harm reduction approach are both based on collaboration between therapist and patient, with an emphasis on increasing patient’s self-efficacy related to goals and changes.

In developing a model of CBT for SE-AN, we apply the core principles of CBT to the goals of harm reduction and enhanced quality of life as defined by the patient. The focus on individualized goals, chosen by the patient in alignment with their priorities and values is based on the recovery model, the harm reduction approach, and the premise that individuals who continue to have severe eating disorders may be helped to lead more full and rewarding lives.

**Time Frame**

The use of a time-limited course of CBT is ideal for SE-AN as this provides a frame for suitable goals, momentum for using the time well, and a
defined commitment of time and energy. Additional courses can be offered at intervals to patients for whom this is a desirable and effective form of treatment. In our evaluation of CBT for SE-AN, the course of treatment was 30 sessions over the course of eight months (Touyz et al., 2013). To the extent possible, we advocate twice weekly sessions for the first four weeks in order to facilitate a strong start.

**Defining Treatment Goals**

Although it is always important for the therapist and the patient to agree on the goals of treatment, this is essential with SE-AN. Patients may be pleasantly surprised by a therapist who is interested in their goals and does not assume or insist that weight gain and improved eating are the primary goals. The therapist should be open about valuing these changes, but also about seeing changes that the patient wants to make as the top priority. Feeling discouraged or hopeless about life may make it difficult for the patient to imagine what their goals might be. Therefore, discussion of possible goals may take some time. Harm reduction goals are guided by the overarching principle of reducing the negative impact of the eating disorder to enhance quality of life without the expectation of full elimination of the eating disorder symptoms. In this context, eating disorder treatment goals are specified in the service of achieving other quality of life goals. For example, if an individual with SE-AN is feeling socially isolated and would like to have more fully engaged friendships, therapy goals around the eating disorder symptoms will be articulated to the extent that they will help the individual achieve these broader quality of life goals. Rather than striving for weight gain that would put the individual in the “normal” range with resumed menstruation, the goal may be limited to sufficient weight gain to increase ability to participate in life activities and increased caloric intake and food variety to facilitate participation in social settings where food is served. CBT for SE-AN may also focus on participation in appropriate medical or dental care and cessation or reduction of behavior that is either dangerous or requires the patient to be in a dangerous situation. Quality of life goals for individuals with SE-AN often include feeling less lonely, fitting in with others, having a role or relationship with others outside of the patient role, being a contributing member of society, feeling better physically, or being able to eat in a social situation. Although the list of possible goals is extensive, the early therapeutic task is to identify one that is a high priority for the patient and has high probability for success.

Before moving toward an action plan, the goal should be specified in definite and measurable terms. For example, a broad goal of reducing social isolation may be operationalized for the current course of CBT as developing one or two specific relationships or attending a social activity once or twice weekly. This might be further specified by naming the
individuals or social activities so that the goal becomes to find, join, and attend a book club or art class or to see my nieces and nephews at least weekly. Similarly, if improved eating is the goal, this should be defined in specific terms so that it is clear what foods are to be eaten and how often. It is essential that the operational goal be sized such that it can be achieved within a few months.

As with other forms of CBT, a good beginning is very important. Early change in an area that is valued by the patient may build hope and confidence that change is possible and that the therapy can be helpful. Early change may be promoted by the identification of a small, achievable goal and the delineation of the specific behavioral steps needed to achieve it. Careful planning and negotiation are needed to ensure that the patient “owns” the goal and views the planned steps as within her reach. In order to capitalize on the benefits of early success with change, the primary first goal of treatment is for the patient to be successful. This may be facilitated by breaking a larger goal into sub-goals or by choosing a goal at the easier end of the spectrum. Another version of this strategy may involve focusing on quality of life goals to build mastery and inspire hope and then circling back to a discussion of harm reduction goals later in therapy.

**Case Example**

Sally was informed by her sister that she was not allowed to pick up the new baby because she was too ill and might drop the baby. Sally reported feeling hurt and rejected by her sister; her initial response was to withdraw and stop visiting. Further exploration revealed that Sally did want to be involved with the baby but felt like a “useless, powerless burden.” After re-evaluating her automatic thoughts and considering the pros and cons of trying to have a relationship with the baby, Sally was willing to engage in problem-solving about how this might be possible. Sally and her therapist agreed on a goal of Sally speaking to her sister to identify ways that Sally could safely have contact with the baby. The preparatory work in session included rehearsing how Sally might approach her sister, what she would say, and how she would manage her automatic thoughts after the interaction. If Sally is able to negotiate a way to spend time with the baby, this is expected to improve her quality of life even if her eating disorder remains unchanged. However, at some future point, Sally may be willing to work toward improvements in her eating and health status that would allow for more involvement with the child.

**Addressing Motivation**

CBT for eating disorders has traditionally prioritized the need to focus on motivation for recovery in treatment. Within this context, considerable effort in treatment is spent attempting to enhance motivation to gain
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In CBT for SE-AN, it is important to recognize that motivation to make changes may be different. Consistent with a recovery model (Dawson et al., 2014), patients may be highly motivated to develop a more personally fulfilling life that accommodates aspects of the illness they feel unable to change. By working toward goals that the patient chooses, the battle with the ego-syntonic attachment to the eating disorder may be circumvented or ameliorated. Nevertheless there may be obstacles to change including feeling hopeless about change or about treatment, or feeling frightened or ambivalent about the change. Consistent with Waller’s (2012) analysis of motivational enhancement, we advocate a focus on behavioral change as the best indicator of motivation to use the treatment for the purpose of making meaningful changes.

Patients with SE-AN typically have an extensive treatment history and a set of beliefs about therapists and treatment and how to manage the two. They may be accustomed to receiving support with no expectation of change, feigning agreement with therapist-led goals in order to connect with the therapist, being a source of frustration for therapists, feeling like a treatment failure or feeling that they will be unacceptable if they reveal certain aspects of their situation, thoughts, or behavior. From the beginning, the therapist should make efforts to discuss these beliefs openly along with their potential as obstacles to change. However, it is also incumbent on therapists to demonstrate with their own behavior over time that these beliefs are not supported by the current therapeutic experience.

Case Example

Louise had a long history of SE-AN, was depressed and felt hopeless about changing her situation. She was able to discuss goals she would like to achieve but they were consistently unrealistically high. Through careful exploration, it became evident that Louise wanted to choose a goal that would impress the therapist and that she was not connecting the goal with any plans to change her behavior. The therapist expressed her appreciation that Louise wanted the therapy to go well and suggested that they find a small behavioral goal as a warm up to anything larger.

Expectations that are Therapeutic

The specific goals of CBT for SE-AN are open to negotiation, but the focus on change and the application of effective CBT principles are not. Patients with SE-AN may have had numerous previous treatment failure experiences. CBT for SE-AN is designed to assist patients in rethinking treatment goals, validating goals that are focused on harm reduction rather than symptom elimination, and encouraging realistic, incremental
progress. This strategy is designed to promote success and nurture the belief that the patient can benefit from treatment and that change is possible. Whether the patient actually does make changes during this course of treatment may be attributed to a confluence of the patient’s internal functioning, life circumstances and events, and the treatment. Appropriate recognition that change has multiple determinants allows the therapist to retain the belief that change is possible even if it has not happened in the past.

The therapist should hold the patient fully accountable for actively participating in high quality treatment. Although the prioritization of therapy goals may be different from traditional CBT, CBT for SE-AN is consistent with traditional CBT in the expectation that the patient act as their own expert and advocate by actively engaging in goal setting and treatment. The therapist continues to take responsibility for the effective implementation of the CBT and is careful not to offer a diluted version of the principles. Completion of agreed upon behavioral experiments or other homework tasks is expected. The exact nature of these tasks needs to be negotiated during the treatment session so that the patient agrees that the tasks are manageable and realistic and the therapist agrees that they are directed toward achieving the identified treatment goals. The therapist may need to be especially attentive that there is concordance between the tasks and the patient’s intentions, skills, and resources related to completing the tasks. Great care should be taken in setting the homework tasks as this is the primary area for early success.

Honesty related to the treatment goal, the patient’s situation in connection with that goal, and the patient’s intention of completing a specific task, is an important expectation. This may require teaching the patient how to openly state disagreement or refusal, a significant challenge for individuals who have a long-standing pattern of pseudo-compliance or conflict avoidance. Similarly, patients are expected to report back honestly on accomplishments and difficulties. An inclination to minimize, exaggerate, or misreport is not unusual and should be discussed openly. In the context of treatment goals which are focused on harm reduction or development of a more personally fulfilling life, urges to misreport may indicate that the sub-goals or the homework tasks are too difficult or that they are misaligned with the patient’s priorities.

**Treatment Non-negotiables**

With SE-AN, treatment non-negotiables include accepting regular medical monitoring and urgent care if needed. Weight needs to be monitored regularly even if weight gain is not a goal. The conditions under which the CBT will end or be put on hold should be made very clear at the beginning of treatment. These may include deterioration in the patient’s physical or medical condition beyond a specified level or the absence of evidence
linking the treatment with beneficial changes. Regular attendance, advance
tonification of absences, participation during sessions, and completion of
homework are expected.

The Strategy for Change in SE-AN

The transtheoretical model of change identifies five general levels of
change (Prochaska, Redding & Evers, 1997). When individuals present
for treatment, they are frequently struggling with problems in multiple
areas of their lives, and the struggle in one area is often linked to another.
The five levels that are identified in the model are symptoms, maladaptive
cognitions, interpersonal problems, family/systems problems, and
intrapersonal problems. The transtheoretical model recommends that
treatment interventions consider these different levels and intervene at
multiple levels to promote the most long-lasting change. To some extent,
these different levels of change represent ever expanding concentric
circles. Within a traditional CBT intervention aimed primarily at treating
the specific eating disorder symptoms, the strategy is to begin at the
center with the core symptoms and maladaptive cognitions. As these
fundamental aspects of the disorder are treated, therapy moves to more
distal factors. In contrast, CBT for SE-AN aims to begin with a focus on
improving quality of life and focuses on addressing the eating disorder
symptoms in the context of this broader goal. Without the expectation
of eliminating all aspects of the eating disorder, therapy begins in the
“outlying” regions where the patient is more ready for action. However,
because the different areas are all connected, a change in one area may
have a ripple effect on other areas.

Strategies for Enhancing Motivation in CBT Focused on Harm
Reduction or Quality of Life Goals

The following strategies are especially suited to enhancing motivation for
change in patients with SE-AN. Because the aim is to work toward changes
that the patient views as currently important to them, the motivational
work may focus on the identification of goals and the instillation of hope
that change is possible.

1. **Help the patient articulate their values so that both patient and
therapist have a shared understanding of what is important to the
patient.** Allow for the inevitable reality that patients really do have
and will construct an understanding of their world that is different
from that of the therapist. What do you value in life? What helps or
might help you to feel that your life is personally fulfilling?

2. **Respect the patient as the expert.** It is extremely helpful in motivating
patients to adopt a posture of “you know, you tell me.” By doing so,
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therapists circumvent power struggles and validate the notion that there is no singular correct answer to complex problems.

3. **Evaluate meaning.** Explore the meaning of the patient’s situation. They may believe that they are not entitled to try to improve their life or relationships unless they give up their eating disorder. Using cognitive tools, such as analysis of dysfunctional thoughts and decision analysis forms, can help articulate the meaning of certain behavior for the patient and help clarify options for experimentation.

4. **Avoid the bait of taking responsibility for the solution.** It is important to remember that the therapist can’t want “it” too badly, whatever “it” is. “It” will have to be decided by the patient. The best the therapist can do is to help the patient make their decisions with open eyes.

5. **Have patients project forward.** Ask your patient where they want to be in five, ten, 30 years. Sometimes it is useful to ask patients to write their own obituary. What do you want to be remembered for? Your eating disorder may be part of the story, but what are the other aspects?

**Specific Cognitive and Behavioral Interventions for SE-AN**

When the goal relates to gaining some weight, improving nutritional status, or reducing the frequency of a specific symptom, standard CBT approaches for eating disorders are appropriate (Pike, Carter & Olmsted, 2006; 2010). These will not be described in detail here but include the development of behavioral goals each week, self-monitoring of target behavior, stimulus control strategies, cognitive rehearsal, and problem-solving related to obstacles that are encountered or anticipated. It is essential that the goal be clearly and specifically defined so that progress can be evaluated. The therapist needs to pay careful attention to ensure that the planned homework is viewed as manageable by the patient. This can be facilitated by asking the patient to set the goals and the homework for the week and then engaging in a collaborative evaluation of the difficulty of the required steps. The guiding principle is to keep early steps small and attainable and to devote significant time in session to planning and problem-solving how the required steps can be taken.

Many goals aimed at improving quality of life will require a focus on building character and behavioral strengths and assets. Some behavioral strategies for developing skills relate to enhanced stress management, enhanced problem-solving, assertiveness training, building healthy friendships, and promoting emotional and physical self-care. Although the identified problem or area for change might be large, a specific and definable goal needs to be chosen. As with other types of CBT, the weekly work is comprised of behavioral experimentation in the form of planned homework, cognitive rehearsal, and problem-solving related to expected difficulties.
Case Example

Vera’s extended family had a tradition of meeting at the same restaurant for breakfast on Sunday mornings and had made it clear that if she was not eating they would prefer to visit with her in a different setting. Vera understood the rationale, but knew that she would miss out on a fun family gathering if she did not attend the breakfast. Her goal was to eat at the family breakfast. Steps involved in working toward this goal included selecting a suitable item from the menu, to practice eating this item at home, and anticipating and preparing for questions and comments from family members who were not accustomed to seeing her eat. Vera was clear that her goal was to gain admission to the social event and not to increase her eating. Therefore, the therapist understood that Vera would eat less elsewhere in the day to compensate for the breakfast and that increasing variety in the meal ordered was not a goal. By eating at the breakfast, Vera gained increased social contact with her extended family and a stronger feeling of connection through shared experiences.

Every Session has an Internal Structure

This structure should be maintained collaboratively. This is NOT a therapist-led treatment; therapist and patient work together on each component of the session. Each session should include the following components:

1. Weight assessment
2. Review of homework
3. Setting an agenda
4. Working on agenda items
5. Summary of session and setting homework

Content of Sessions

With each successive session, the therapist and patient build on the behavioral homework task from the previous session. To the extent that cognitive distortions interfered with the patient’s successful completion of the task, these are identified and examined. To the extent that the task was accomplished successfully, the therapist and patient decide on the next logical step and establish that as the behavioral homework assignment.

Cognitive Distortions

Cognitive distortions and automatic thoughts are derivatives of an overarching cognitive set or schema that governs an individual’s experience and behavior (Beck et al., 1979). Attempts to change behavior may provoke thoughts that support the status quo and undermine change.
These thoughts can be caught and challenged with dysfunctional thought records, self-talk, and behavioral experimentation.

Similar to others, patients with SE-AN are likely to have their thinking shaped by cognitive distortions related to black and white thinking, overgeneralization, use of a mental filter, disqualifying the positive, jumping to conclusions through mind-reading or fortune-telling, catastrophizing, emotional reasoning, should statements, or personalization. However, because individuals with SE-AN may have a long history of keeping their thoughts to themselves, some of their beliefs may be deeply ingrained and uncontaminated by challenges from others. This, combined with rigidity or perfectionism, can make it difficult for patients to accept the premise that their thinking and their beliefs are not permanent and unchangeable aspects of the self but can be considered and evaluated separately. Although the process used in CBT to work with thoughts and beliefs is no different with SE-AN, the strength of the attachment to long-held but unhelpful beliefs dictates a careful and comprehensive approach. This does not mean that the core belief must be fully challenged and revised before change can occur. Progress can be made by “working around the edges” with a focus on addressing the beliefs to the extent needed to allow the patient to work toward the specific behavioral goals identified for this course of treatment.

Schema-based CBT

One of the most striking features of AN is the all-encompassing nature of the disorder. For the patient, family, and professionals working in the field, AN dominates the characterization of the individual. It is not uncommon for the individual with the disorder to refer to herself as “an anorexic” rather than as someone with AN. In the former, the anorexia comes first and serves as the umbrella under which the individual stands, and in the later, the individual constitutes the larger whole, a person with the problem of AN. Although the distinction may not appear significant at first glance, the former characterization reflects and reinforces the centrality and all-consuming nature of this disorder.

One goal of therapy is to make explicit the all-encompassing role that the AN plays in organizing and simplifying an individual’s self-concept and experience. As described by Vitousek and Hollon (1990), the cognitive schema characteristic of AN serves several purposes. It reduces ambiguity in the individual’s life by providing a structure on which to base judgments, predictions, and rules for decisions and behavior. Central to the core cognitive schema of AN is the overvaluation of weight and its importance in determining self-worth and establishing a self-concept. Although altering this core cognitive schema would be a strong focus in traditional CBT for AN, in the case of time-limited work with SE-AN, the goal is to carve out some space for other aspects of life. There is no
attempt to eradicate the core cognitive schema, the aim is to reduce its all-encompassing role by developing other aspects of the self.

Adapting the pie diagram in Figure 8.1, the therapist estimates with the patient the percentage of the pie that is encompassed by the eating disorder schema. Typically, at the beginning of treatment the majority of the pie will be accounted for by the eating disorder with little else elaborated. The next step is to articulate what the patient would like her pie to look like. This will demonstrate what aspects of life and of self are most valued by the patient and can be used as a reference in developing and maintaining a focus on goals in areas that are valued by the patient. The proportion of the pie that continues to be occupied by the eating disorder is not the focus in this context (see Figure 8.2). Rather, the pie diagram is used as an aid to the elaboration of other aspects of the self that are of interest or value to the patient. If the patient starts treatment with the self-schema “I am an anorexic” and moves to the self-schema “I am a person who has anorexia nervosa and I enjoy art,” this is a worthwhile accomplishment.

**Cognitive Schemas that are Common in Individuals with SE-AN**

In addition to the eating disorder schema, other maladaptive schemas are common and may contribute significantly to the patient’s everyday life. Many of these have some basis in reality. It is the dominant, singular, and extreme nature of the belief that we view as both distorted and maladaptive. Parallel to the treatment goals related to specific and limited changes, the aim is to address the schema to the extent that they block behavioral experimentation and movement toward improved quality of life. The following are a few examples.
I am a Failure

Individuals with SE-AN may view their illness as a failure that cuts across all aspects of their life and defines their future. Personalization may be at work to shape the belief that the illness is their fault, even though they may accept that other people should not be blamed for having an illness. The practical goal in time-limited CBT for SE-AN is to create a niche of separation from this belief that allows the patient to move forward with the planned behavioral experimentation. Being informed about the patient’s cognitive set allows the therapist to anticipate potential obstacles and work with or around them. For example, if the goal is to increase the variety of foods that the patient is willing to eat, the therapist watches for unrealistically high expectations, the anticipation of failure, and insufficient planning and rehearsal for behavioral homework (i.e., thoughts and behavior that are consistent with a failure schema). The approach is to establish a small list of foods that the patient would like to be able to eat, discuss the rationale for each food on the list and reject items that are too hard, create a hierarchy based on expected difficulty and identify one item at the bottom of the hierarchy as the immediate goal. Extensive planning, problem-solving and cognitive rehearsal occur in session before any behavioral homework is assigned. The idea is to be slow and cautious in an endeavor to maximize the probability of success. Behavioral experiments are thoroughly debriefed at the next session for the purpose of revising the plan if there were problems and identifying useful strategies and strengths for additional use moving forward. Cognitive work aimed at re-evaluation of the “I am a failure” schema is not the focus, rather, the emphasis is on building a strategy for a small and specific change in behavior. Nevertheless, the therapist encourages the patient to include the successes made in treatment in her self-schema.

I am a Burden

Family members and friends of an individual who has a severe and enduring illness may experience both instrumental and emotional burden. They may also like the ill person, enjoy their company, and want to support and help them. The patient may need to acknowledge that, at least in theory, her relationships might be multi-faceted and that these other aspects are at least possibilities. The patient’s initial reaction to a possible goal of increasing social contact with family members might be that she would like that but that it is unacceptable because it would increase the burden on family members. In the patient’s schema of herself as a burden, she imagines that increased contact means higher frequency burdensome tasks for others. The approach is to generate potential forms of contact that are either not burdensome or provide some benefit to the
family member. For example, one patient knew that her mother did not like to do internet research or make phone calls to find services or arrange appointments for herself, tasks that the patient was comfortable with and could do without leaving her home. Helping her mother in this way created a need for increased phone contact with the mother to discuss the project and report the findings. In addition, the mother was appreciative of the help and expressed this to her daughter.

**It is Dangerous to have Feelings**

For many individuals with AN, emotional expression has been subjugated and dissociated from experience. They may see feelings as untrustworthy, scary, and dangerous to express. They may also identify this as an aspect of life in which they are deficient and would like to become more competent. Learning to identify emotions and link them to corresponding thoughts and experiences can be facilitated by including emotions as part of the experience when the patient reports back on her homework tasks. Weaving emotional expression into the review and debrief may feel manageable to the patient, especially if the emotions are of lower intensity in the early stages.

**Affect Regulation and Interpersonal Effectiveness Skills**

Many individuals with SE-AN have difficulties related to affect regulation and interpersonal relationships. Attempts to make changes in other areas may highlight deficiencies in these areas. In time-limited CBT focused on harm reduction or improved quality of life, the focus is on acquiring the skills needed to meet a specific behavioral goal. In the earlier example, related to Sally and her goal of spending time with her newborn niece, the work included interrupting Sally’s tendency to withdraw and isolate as a way to manage her hurt feelings and developing and role-playing a script for approaching her sister to identify acceptable ways for Sally to spend time with the baby. Although the scope of the work in this area is more limited than in traditional CBT, the approach is similar and involves enhancing the patient’s ability to self-regulate and successfully manage interpersonal situations. It may be useful for therapists to adapt some of Linehan’s (2015) exercises aimed at enhancing emotional regulation and interpersonal effectiveness. These interventions are based on sound cognitive behavioral principles and may be effectively adapted for patients with SE-AN. Planning and preparing for a behavioral experiment which involves interacting with others provides the opportunity to develop a strategy for interpersonal effectiveness. This may be done in a limited way, analogous to an applied tutorial focused on the task at hand, or with more breadth if the focus of the treatment goal is on increasing interpersonal effectiveness.
Using the Therapeutic Relationship to Address Maladaptive Thoughts and Schemas

The therapist can make use of the therapeutic relationship to explore the patient’s more general feelings and assumptions about interpersonal relationships. For example, many patients describe problems with trust, autonomy, and assertiveness, and worries related to being rejected, abandoned, or disliked. The therapist can use the relationship in vivo to help the patient articulate assumptions about the relationship and to evaluate their accuracy. Some work of this kind may be a necessary prelude before the patient is willing to share some of the thoughts that she finds shameful or unacceptable. Similarly, it may require significant work for the patient to be willing to openly disagree with the therapist or refuse a task suggested by the therapist. However, this is essential in CBT with SE-AN to ensure that the goals match the patient’s priorities and the homework tasks are viewed as relevant and achievable.

Ending Treatment and “Relapse” Prevention

In connection with CBT for SE-AN, relapse is conceptualized as losing the gains that have been made during treatment. Although we would not use the term this way in an empirical study, using it clinically denotes that the patient’s accomplishments are substantial and meaningful, provides a framework for ongoing vigilance, and identifies a collection of strategies that may be helpful in preventing relapse.

In preparing for the termination of treatment, the therapist and patient review specific CBT tools and strategies that the patient has found most helpful. This is the time to take stock of what has been accomplished and to reinforce feelings of self-efficacy. It may also be important to identify perfectionism as a cognitive set that can defeat the patient’s growth by minimizing and devaluing the steps they have made and discouraging them from further progress.

The therapist helps the patient think ahead to potentially challenging situations and to practice and plan for these challenges. Anticipation and planning are key elements in preventing relapse. However, the therapist also emphasizes that no one stays exactly on course 100% of the time. As much as possible, the therapist helps the patient learn to identify and monitor cues that she is “off course.” The more attentive and responsive the patient is to such cues the less likely she is to relapse. It may be helpful for the patient to develop a list of risks for relapse and a written plan for managing at these times. Patients are encouraged to review the CBT materials from therapy and to continue practising this approach on their own.

The patient’s experience with the therapist may have been very meaningful to her. Being accepted by the therapist may have reduced the misery of feeling unacceptable and misunderstood. If the patient made
changes during treatment she may feel that the therapist is the only one who can help her, since so many others have tried and failed in the past. Throughout the treatment and with increasingly explicit reference, it is helpful to discuss the possible feelings of loss that are associated with ending treatment. It is useful to help patients express their feelings and to plan for how they will take care of themselves in the face of such loss.

The conditions for having another course of CBT in the future should be explicit. Although patients with SE-AN may need ongoing medical monitoring and a range of supportive services, these are not needs that require ongoing CBT. For traditional CBT as well as CBT for SE-AN, the expectation is that individuals will be actively engaged in setting goals and making changes in their lives to achieve these goals. This requires a commitment of time and energy. In our experience, it is useful to set a time-limited course of treatment that is followed by a period of consolidation and rest. The break between courses might be several months or longer in order to emphasize the distinction between periods of consolidation and rest and periods of work focused on change. Given that such work is never fully completed (for anyone), it is reasonable to anticipate that individuals with SE-AN may seek additional courses of treatment over time. To the extent that they find CBT for SE-AN helpful and are successful in their efforts, they will be more likely to secure additional help as needed in the future. Ultimately, the goal of CBT for SE-AN is to empower individuals to address their thoughts, feelings, and behavior in ways that enhance the quality of their lives, so that they are able to develop more fulfilling, joyful, and meaningful lives. The initial findings evaluating CBT for SE-AN suggest that we are on the right track.

References


9 Administering Treatments for Severe and Enduring Anorexia Nervosa

Examples from Treatment Experiences

Colleen Stiles-Shields, Bryony Bamford, and Lucy Serpell

This chapter provides insight into the experiences of therapists and clinical supervisors administering cognitive behavior therapy (CBT) and specialist supportive clinical management (SSCM) for severe and enduring anorexia nervosa (SE-AN). The respondents have experience providing both treatments in research and clinical settings. The experiences are detailed in an interview format, enabling the exploration of more clinical issues, such as comorbidities and variety in challenges and rewards, than a single case study may provide.

What are the Unique Clinical Aspects of CBT and SSCM as Experienced by a Clinician Treating SE-AN?

CBT is an active therapeutic approach that utilizes theory-driven strategies to achieve overall treatment goals. A major strength of CBT for SE-AN is a therapist’s ability to identify and develop an explanatory formulation to help the patient to understand the disorder, contributing factors, and what maintains it. Each session commences with establishing an agenda that is an equally collaborative agreement between the patient and therapist regarding what will be covered. Hence, therapists have a direct opportunity to include in the agenda deliberate attempts to discuss and implement strategies that the therapist believes will be of direct benefit to the patient. Additionally, active strategies must be present for the therapist to confidently state that CBT is being effectively administered. These strategies include completing food diaries, cognitive restructuring, and behavioral experimentation. The acquired ability to teach skills effectively is therefore a key aspect of administering CBT.

SSCM is a more flexible approach, which can sometimes feel like “doing CBT while sitting on your hands.” When patients are ambivalent about change from the current state of their disorder, it can feel like a relief to therapists to work in a less structured therapy that allows the focus to be determined by the patient. A therapist’s role is to be supportive, conduct
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basic medical monitoring, and review overarching treatment goals that are dictated by the needs, feelings, and desires of the patient. The therapist does not contribute unsolicited skills or techniques to the agenda, as SSCM maintains that the patient already holds the skills needed to make progress in treatment. In this sense, the therapist works to build upon a patient’s pre-existing strengths rather than supplying a new set of skills. The formulation is informed by the knowledge that the patient has developed disordered eating due to a unique combination of factors. Therefore, treatment is unique to each patient, developed through a combination of the patient’s knowledge of what interventions are personally effective and the therapist’s knowledge about what strategies may contribute to recovery. Active strategies are never enforced, but may be discussed and utilized if suggested by the patient.

Who Does Each Treatment Suit From a Clinician’s Perspective?

CBT is well suited to people who seek a more active treatment, involving guidance and direction from the therapist. Patients with SE-AN well suited for CBT tend to be more motivated to engage actively with treatment, including a willingness to complete homework between sessions and to explore and engage with their cognitions. Patients must be prepared to explore and share underlying thoughts and fears with the therapist, a step that goes beyond providing surface details and descriptions of current experiences. Beyond willingness and motivation, a certain degree of insight and emotional intelligence is necessary for patients to identify connections among their cognitions, emotions, and behavior. A specific factor that may impact willingness to engage in CBT is previous treatment experiences. Some patients who have had previous treatment experiences with less-structured psychotherapy have described CBT as feeling uncomfortable and overly structured for the first few sessions, while others have welcomed the more containing experience of a structured therapy. Socializing the patient appropriately to the demands of CBT can ease the transition into CBT for all patients who are new to the approach.

SSCM is well suited for patients who want a flexible approach or are ambivalent about change, enabling them to create their own agenda and talk through issues of which they are already aware. SSCM can be suitable for patients who are less motivated to engage in an active therapeutic process or who have engaged in many previous therapeutic approaches with little success. Patients with comorbid personality disorders are also well suited, as a shorter-term cognitive approach may not be sufficient to evoke changes in core schema. The flexible treatment approach of SSCM enables patients to focus on their current situation, the therapeutic relationship, and on improving quality of life, despite the existence of negative core beliefs or behavioral symptoms. Specific to SE-AN, some of our patients have been acutely aware of their automatic thoughts and
alternative thoughts based on evidence, yet could not move forward due to an entrenched “anorexic identity” or paralyzing fears of recovery. For such individuals, SSCM provided a less structured, flexible exploration of the present circumstances at a slower pace.

The Work of Le Grange et al. (2014) Indicates that Patients with Higher Baseline Eating Disorder Pathology, Depression, Older Age, and with Binge Eating/Purging Subtype Benefit More from CBT than SSCM. Are there Patient Characteristics That Would Inform your Decision on What Treatment to Give?

The greatest risk that therapists and treatment teams encounter in working with patients with SE-AN comes from preconceived assumptions about the inability of individuals to utilize psychotherapy. We are cautious to make any definitive statements about what patient characteristics determine the choice of treatment modality. Patient choice is an important factor that should not be overlooked. Following an adequate psychological assessment, we have found it beneficial to decide with patients which treatment they prefer, based on their motivation, previous treatment experiences, and preferences for therapeutic style. As CBT relies heavily on an explanatory model of eating disorders, it is particularly helpful in a patient’s understanding of how restriction and bingeing maintain one another. This insight is of particular benefit to those with binge eating/purging subtype, as it provides a clear rationale for early treatment behavioral change. This rationale is illustrated through the use of food diaries, enabling patients to see for themselves the link between their restriction and their bingeing. Food diaries are typically a requirement in CBT, but are only utilized in SSCM if suggested by the patient. Patients with complex personality disorders, poor insight due to cognitive capacity, or low motivation to engage in tasks or specific homework tend to prefer SSCM. However, these general clinical assumptions are not intended to inform treatment modality decisions, as an adequate psychological assessment is crucial. Given that the work of Touyz et al. (2013) demonstrates that both treatments are effective for SE-AN, therapists trained in CBT and SSCM have the luxury of being able to offer both options to patients to allow a collaborative decision on treatment modality.

The Work of Stiles-Shields et al. (2013) Indicates that Therapeutic Alliance can be Effectively Established in the Treatment of SE-AN Using CBT or SSCM, and this may be Relevant for Treatment Response, Particularly Late in Treatment, on Some Aspects of Eating Disorder and Depressive Symptomology. What Tactics Improve Therapeutic Alliance while Maintaining Manualized CBT and SSCM Treatment?

Although both treatments enable equivalent therapeutic alliance to form, the process of developing the relationship is often different for
each treatment. Consistent with the work of Waller et al. (2012), we believe that behavioral change in CBT is crucial for the development of therapeutic alliance. The focus on behavior is incredibly beneficial for some patients, such that as they engage in behavior change and recognize positive changes as a result, they feel a greater trust and bond with their therapist. Therapeutic alliance therefore relies heavily on positive experiences of the therapy and outcomes in CBT. However, if a patient struggles with behavior changes or tasks assigned between sessions, or reports that CBT feels too rigid as a treatment, the therapeutic alliance becomes more difficult to build.

In delivering SSCM, therapeutic alliance is the main focus of treatment. Built upon the principles of supportive psychotherapy, including warmth and unconditional positive regard, most of the therapist’s efforts are put into developing an open and trusting relationship. Therapeutic alliance develops in SSCM by adapting therapeutic style to what the patient wants and describes as helpful. If the patient believes they benefit more from challenges, the therapist must push and challenge; if the patient describes success through working slowly and gently, the therapist must be gentle and slow the pace of exploration. The therapist must build their relationship around what the patient needs. This is frequently reflected back to the patient (for example, “I’m starting to wonder if I am pushing you enough, what is your experience of our work recently?”). As with any therapeutic approach, therapeutic alliance forms through being open, honest, human, non-judgmental, and understanding, but in SSCM these qualities become central to all patient interactions, balanced with a focus on weight restoration and risk management.

What Types of Comorbid Diagnoses do your Patients Typically Present with? How do Such Conditions Interact with or Impact both Treatment Modalities? How do Therapists Address Comorbidities while Maintaining Manualized Treatment?

Our patients have presented with a high number of comorbidities, ranging from borderline personality disorder to mood disorders. In the randomized trial, comorbid conditions included mood disorders and dysthymia, generalized anxiety disorder, social phobia, obsessive-compulsive disorder, and substance dependence. About 39% of those randomized to CBT and 44% of those randomized to SSCM were on active doses of psychotropic medication for these comorbid conditions.

Comorbidities are first discussed in supervision to determine whether they contribute to the formulation for each case. If they are included in the formulation, then they may be addressed as part of treatment. If they appear as separate diagnoses in their own right, the focus is on treating the eating disorder first, acknowledging that future treatment will be required for the comorbid condition. In CBT, a therapist addresses comorbidities...
by regarding all difficulties as relating to underlying core beliefs and therefore able to be addressed through CBT strategies, such as cognitive restructuring and behavioral experimentation. In SSCM, comorbidities are addressed if they are named as issues by the patient or if they actively interfere with therapy. A therapist might ask, “How can we stop this from interfering with therapy? How can you help yourself to overcome this issue?” For both treatments, the manuals allow the therapist to name the issue or comorbidity and use the respective treatment strategies to address them, as applicable.

How does the Therapist’s Experience of Working with Patients Change over the Course of Allotted Sessions in CBT and SSCM?

The therapist administering CBT is consciously and gradually handing over responsibility to the patient. The therapist’s task is to provide the patient with a set of skills that are believed to be helpful and to support the patient to adopt these skills as their own. Through this process, the goal is for the patient to become proficient in acting as her own therapist. This process is structured by session, such that the first and second sessions allow for assessment and building therapeutic alliance; the second to fourth sessions allow for building motivation and the formulation; the fifth to twentieth sessions engage in cognitive restructuring and behavioral experimentation; the twentieth to twenty-seventh sessions allow for exploring and challenging core beliefs; and the twenty-seventh to thirtieth allow for relapse prevention and termination processes. The “feel” of CBT therefore changes over time as the therapist’s tasks change as therapy progresses.

SSCM has three phases of treatment, but the transitions are less defined than in CBT. The therapist uses the manual as a guide to assess, treat, and prepare for termination. This flexibility allows for some sessions to feel very similar to one another. The sessions are dependent on the therapeutic alliance and the encouragement the therapist provides each week to support the patient to recognize the necessary skills already possessed to name and achieve goals. Although the goal of CBT is for patients to eventually act as their own therapist, SSCM supports people to come up with their own solutions to their problems throughout therapy. This process enables the patient to learn to be their own resource without relying on the therapist to provide the skills that are believed to help.

What are the Biggest Barriers or Challenges to Delivering CBT and SSCM to Patients with SE-AN?

We have had patients initiate treatment who have had prior experiences with CBT that they found to be negative. This often creates resistance to the important processes of CBT and can result in a slower start to
therapy. We have had to work much harder with such patients in order to engage them and to demonstrate the rationale behind the techniques and processes of CBT. Other challenges arise when patients are not motivated or are unable to challenge their cognitions to evoke change. This latter difficulty arises because although they are able to identify alternative thoughts, such alternatives feel meaningless to them due to the entrenched nature of their eating disorder. At such times, patients tend to get frustrated, which is discouraging to the therapist. Additionally, we once opted to withdraw a patient from CBT as the increased focus on her thoughts cause her to become obsessional and paranoid. Although this was an isolated incident, her reaction to CBT became too detrimental to ethically continue with the treatment.

As our training originated with CBT, SSCM initially felt less automatic and natural. However, given past therapist experiences in which CBT did not “feel” like a good match for particular patients, we were open to SSCM as a therapeutic approach. SSCM has felt like a challenge when patients want the therapist to be more active, particularly in the face of struggling to come up with any of their own suggestions for problem-solving, or being very critical of their own attempts at problem-solving. At such times, therapists may feel frustrated to not be able to “give” more to a patient through coaching in specific skills; as we previously mentioned, SSCM has sometimes been described as “doing CBT while sitting on your hands.” For this reason, SSCM seems less of a challenge when working with a patient who does not desire an active treatment, but rather to feel as if someone wants to understand and listen.

Are there Temptations to Deviate from the Manual for Either Treatment? If so, for what Situations and Symptoms, what have you been Tempted to do Instead, and what are the Results of Maintaining the Manual Despite Temptation to Deviate?

When patients receiving CBT do not engage in homework or are not finding the process of thought evaluation to be helpful, they sometimes request a less structured approach. It is sometimes difficult to stay on track and repeatedly describe the rationale behind uncovering cognitions or core beliefs, or completing homework. In situations where patients disclose past trauma(s), or show acute distress or grief related to current life circumstances or the impact of the eating disorder, we have been very tempted to deviate from the structured, active approach of CBT. At such times, we have wished to employ more generic therapeutic strategies, such as empathic listening and unconditional support. Although these are common and worthwhile therapeutic approaches, employing only these tools means that a therapist is no longer providing CBT. Resisting these temptations, maintaining a focus on the manual has led to greater insight into the role of cognitions and behavior and enables patients to work on
at least one active improvement in their lives. Patients have sometimes given the impression that CBT asks them to work beyond their current abilities. At such times, we have assessed with supervisors as to whether the individual does indeed have the cognitive capacity for CBT. If not, a referral or second opinion may be beneficial.

In SSCM, temptations have arisen if the therapy feels too flexible or not structured enough. It has, at times, felt very challenging to not offer specific cognitive or behavioral strategies when our clinical experience suggests that they might be beneficial to the patient. This has sometimes left a feeling that as therapists, we were not “doing enough,” not offering an individualized formulation to aid in the patient’s understanding of the eating disorder, not teaching specific skills, or not pushing the patient to work between sessions. These temptations are hardest in SSCM, when patients appear to seem stuck in their progression through treatment. At such times, we have relied on a strong focus on the patient’s stated goals, overall and weekly, to identify a personal strength or resource that will aid in moving forward.

**What are the Greatest Benefits and Rewards of Delivering these Treatments?**

In CBT, providing an individualized formulation has been incredibly rewarding with many patients. In going through this process, we have been able to provide patients with a sense of their eating disorder and an organized way to understand it. This often leads to a clear rationale for treatment. There is such pleasure and satisfaction when a patient has a “light bulb moment” and seems to understand and internalize the approach of CBT. At such times, we have enjoyed watching patients take the skills and make them their own; it feels as if we have given people skills for life.

SSCM can feel very gentle and respectful. Patients have reported feeling understood, listened to, not judged, and feeling a sense of trust in therapeutic support and in our experience as therapists. The approach is particularly rewarding if patients have had previous negative therapeutic experiences, such as poor treatment fit, feeling judged, or a therapist’s misunderstanding of them or their eating disorder. Therapists are able to provide patients with the great experience of being listened to and contained; interactions that may, unfortunately, be completely new to them.

**As Clinicians who have Provided these Treatments in Research and Clinical Settings, how would you Envision using this Treatment in a Community Setting?**

Our experience in the trial has led to two specific realizations: (1) relief that as therapists we can apply CBT slightly more flexibly when working in the community, and (2) a real respect for conducting CBT well, according to
the manual. Although they may sound contradictory, our experience speaks to them as truths. In speaking to other therapists, there appears often to be a prejudice against utilizing CBT for people with anorexia nervosa; a view that individuals with anorexia nervosa cannot engage in CBT or are not motivated to do so. Given the evidence base for CBT, this prejudice seems unfounded. However, we would like to see CBT adapted to match more closely to the desires of the patient, for example in the trial we focused on improved quality of life rather than full weight restoration as a goal in CBT. Many therapists who use CBT with other conditions enjoy a quick progression in treatment, which is in line with the short-term, skills-based way in which CBT is often used with patients who are motivated for change. However, in patients with SE-AN, there is a great deal of ambivalence and ego-syntonic attachment to the eating disorder. Therapists using CBT should feel able to be creative in their approach and use supervision to ascertain that they are not pushing a patient beyond their current abilities. Such actions could reinforce a sense of failure and negative experiences of treatment. Additionally, recent developments in CBT have begun to incorporate more explicit techniques to address motivation. This work has begun, but we hope that it is soon more embedded within the approach for patients with SE-AN. Our hope is that all clinicians view CBT as a potentially worthwhile and effective treatment for patients with SE-AN.

We believe that SSCM should be offered in the community as a fixed-length treatment option. Our experience in speaking with other clinicians is that SSCM is sometimes provided in community settings in an unplanned, ongoing basis, without a projected termination date. This may give the impression that SSCM provides more of an ongoing relationship and time to “chat” rather than being a viable therapeutic approach with specific goals. We fear that this reputation leaves therapists believing that SSCM is for patients who are believed to not benefit from any type of treatment. Our research and clinical experience with the successes of this treatment argue against such assumptions. In the community, SSCM might be a good first step in the therapeutic approach, particularly for those who are opposed to therapy or are at a low level of motivation. The experience of being able to set their own goals and work toward them in an atmosphere of warmth and positive regard can be incredibly beneficial, even to patients who do not make large changes in their body mass index (BMI). SSCM is anything but an “end of the road” treatment, but rather a possible treatment modality where patients can, within a fixed time period, make as much progress as within CBT.

For both treatments in the community, we believe it may also be beneficial to have more explicit involvement of caregivers and loved ones in treatment. This is increasingly being incorporated within other approaches for anorexia nervosa, such as the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA) (see data supplement DS1 in Schmidt et al., 2012).
Conclusion

Our experiences of CBT and SSCM with our SE-AN patients have made us strong advocates and frequent utilizers of both treatments. Although the two treatments differ in strategies and formulation, they are both efficacious, allow for the development of strong therapeutic alliance, and provide many rewards to clinicians and patients alike. Challenges and barriers can be addressed and overcome in both treatments, particularly with supervision. Given the benefits of both, clinicians are recommended to gain expertise in CBT and SSCM, enabling them to collaborate with patients to determine treatment modality together. Our experience in treating this population with CBT and SSCM has provided a real sense of empowerment. We can confidently state that these treatments provide the opportunity for clinicians to aid and support patients with SE-AN in enacting significant change and improvements in their lives.

References


10 Who is Best Placed to Treat Clients with Severe and Enduring Anorexia Nervosa?

Bryony Bamford, Victoria Mountford, and Josie Geller

This chapter aims to consider who is best placed to engage and treat individuals with severe and enduring anorexia nervosa (SE-AN). Although at first glance, this may appear to be a question with a straightforward answer, there are many considerations, reflecting different approaches, goals, resources, and many more issues. How can we achieve medical safety and improved quality of life while reducing the risks of entrenchment in the eating disorder, revolving door admissions, and carer distress? In meetings with our colleagues—nationally and internationally—we are aware of the debate in many arenas about who is treating these patients. To date, there are no evidence-based guidelines regarding who is best placed to treat individuals with SE-AN, or what this treatment might look like (Hay, Touyz & Sud, 2012).

A second question might be: “Why is it important to think about who should treat?” As we will attempt to convey in this chapter, this is key. As earlier chapters have demonstrated, individuals with SE-AN often have lives that are limited physically, emotionally, occupationally, and socially. They may be vulnerable and have low self-esteem. It is likely that individuals may have been through treatment programs that they have experienced as aversive and they may shy away from further treatment. Some have shared with us how they feel that treatment is another thing they have “failed at.” Treatment aims may differ from conventional goals, instead focusing on improving quality of life and functioning, akin to the recovery approach (Bamford & Mountford, 2011). To support individuals with SE-AN and to enable them to keep themselves safe requires skill and dedication. The nature of this work can lead to the risk of burnout, hopelessness, and exhaustion.

Aims and Scope of the Chapter

Given the scarcity of guidelines, in this chapter we will be using our clinical experience to offer thoughts, ideas, and guidance regarding this patient group. We stress that we are not setting “rules” and that our reflections are guided by our own experiences. Two of us (BB and VM) are clinicians
working in the private and public sectors of the United Kingdom and the third (JG) practices in Canada. We aim to explore the debate regarding treatment in specialist or more generic, community-based services, to outline possible differing models of care for individuals with SE-AN, and to consider the variety of individuals and organizations that may be involved and their roles and the qualities that might be invaluable in working with this population. However, we will start with hearing from those who have experienced SE-AN and their thoughts on who should treat.

How do Individuals with SE-AN View their Treatment Needs?

In considering the questions of “who is best placed to treat SE-AN clients,” it is crucial not only to utilize research findings and clinician experience, but to learn from the experience of SE-AN clients themselves. Many of these clients will have been through a number of different treatment experiences: being treated in different settings, using different models, and by different professionals. With this in mind we ran a series of focus groups with SE-AN clients during which they were asked about the limitations and strengths of treatment approaches previously offered to them, as well as the aspects of treatment that they believed would most benefit them. We recognize the limitations of generalizing from a small series of focus groups to SE-AN clients as a whole; however, we think that the themes that emerged from these conversations remain highly relevant and worth incorporating alongside our own clinical impressions. We will break these themes down into “difficulties with treatments offered” and “perceived solutions to these difficulties.”

Difficulties with Treatment Offered

*Treatment not Fitting Needs*

Clients spoke about the mismatch between the treatment options available to them and their own needs and priorities. Treatment was often focused on goals that felt unattainable to them, such as full weight restoration or complete remission of all eating disorder symptoms. There was a sense that there was nothing in between that could help them get to a stage where these goals may feel more realistic. This often meant that they were either excluded from treatment options, or that they were included but discharged when they struggled to comply with treatment goals, reinforcing their sense of failure and their lack of faith in clinicians and treatment. The alternative was that they were offered treatment that did not push or challenge them to progress. They were merely “monitored” to ensure that they were not deteriorating, but were not expected to make positive changes. This resulted in a sense of stagnancy, where clients achieved medical stability but were not given the support to move forwards, perhaps outside of their comfort zone.
Transitions

Transitions between different parts of a service were often viewed as particularly difficult times. These transitions included inpatient to outpatient or day-patient services, as well as from specialist to generic mental health teams. Clients felt that they were often moved between clinicians with no overlap and no continuity of care, meaning that at a time where their eating disorder was being most challenged, they also received the least support, often having to engage with a new practitioner at the same time.

Intensification of Treatment as Medical Risk Increases

Clients spoke about the confusion they experience when they get more care as their medical risk increases. It leaves them feeling that the only way to get more support or more input is to reduce their weight, or increase symptoms, rather than to communicate that they are struggling and therefore need to access more support.

Unskilled Professionals

A common theme among SE-AN individuals was that they viewed services as often “dumping” them with the less skilled or less qualified staff members. There was a sense that it was seen as a “waste of resources” to utilize highly skilled professionals, and that these are reserved for people with higher levels of motivation or who are medically unstable, rather than individuals who have struggled with an eating disorder for a long time but are relatively stable. There was also a view that if they questioned a treatment approach offered, they were viewed as “demanding” or “unrealistic,” a sense that can serve to reinforce a negative self-view.

Negative Assumptions

SE-AN clients reported constantly battling negative assumptions from clinicians. They were seen as “a lost cause,” “a pain,” “a hopeless case,” “being untreated.” These negative and damaging assumptions were often communicated to clients, either explicitly or through subtle comments. This was seen as the most damaging aspect of care to individuals with SE-AN as there was a strong sense that to hold the hope and the possibility of recovery was essential to them at times when they may have given up on themselves.

Abrupt Endings

Clients talked about the difficulty of treatment ending often abruptly in an unplanned way.
Communicate “Why” not “What”

The communication style of clinicians was named as an issue by a number of SE-AN clients. They were often told “what” would happen but not “why” that decision was made, leaving them feeling that they were being persecuted, undermined, or disempowered. In addition, unskilled practitioners, who perhaps do not understand the complexity of disordered eating, could often make unhelpful comments about weight or eating.

Perceived Solutions to Difficulties

During the focus groups, SE-AN clients were asked to recall positive treatment experiences, or to contribute ideas of what they thought would be beneficial to them making progress. The following themes emerged from this aspect of the focus groups.

Support Groups on Transition

A group for individuals who are gearing up to or are undergoing a transition to a different part of the services was seen as highly beneficial. This was thought to help with normalizing the emotions associated with transitions and provided support in overcoming the challenges associated with transitions.

Peer Working

An idea put forward was to utilize individuals who have first-hand experience of disordered eating to provide support or motivation. Peer working has been effectively implemented in general adult services but is underutilized in this field and to our knowledge there are no published outcome studies. Instead, it appears that such support has sprung up on a more ad hoc basis, often led by third-sector or charity organizations. We believe that peer workers can prove valuable role models and provide alternative perspectives to clinicians. In support of this, a qualitative study (Turton et al., 2011) found that patients with eating disorders viewed peer working as potentially highly beneficial. Peer support clearly warrants further development within the field.

Small Supportive Practical Groups

Practical, rather than therapeutic, groups were found to be incredibly beneficial for SE-AN clients—groups that focused on living skills, such as cookery, shopping, and budgeting to assist SE-AN clients in living in the community with their eating disorder.
**Assertive Outreach/Community Working**

Having someone to support change in vivo rather than just talking about change within the confines of a therapy room was found to be very helpful.

**Structured Goal Based Treatment**

A strong theme that emerged concerned the importance of having a treatment that pushed clients to the right degree. They felt that they did not necessarily benefit from “monitoring,” but needed a treatment approach that encouraged and facilitated change, did not enable complacency but equally understood that change was likely to be slow. Explicit discussion of short- and longer-term therapeutic goals that were agreed collaboratively, and were reviewed on a weekly basis, was found to be beneficial by most people that we spoke to.

The themes that emerged from these focus groups are ones that we agree with clinically. Both the difficulties described and the solutions put forward are things that we have viewed within clinical practice. It is crucial to remember that individuals with severe and enduring mental health difficulties will almost undoubtedly hold entrenched negative self-views that will influence how they perceive their treatment experiences, as well as, in some cases, evoke a treatment experience that reinforce these negative self-views.

In the following sections of this chapter, we aim to outline some of the debates that exist around the effective treatment of SE-AN clients. We will also provide our thoughts on how services may be able to match treatment requirements of SE-AN clients with clinician and service resources.

**Treatment within Specialist versus Generic Services**

Complex SE-AN patients will at times require access to multidisciplinary teams that are resourced to address multiple comorbidities and severe symptomatology. Such environments may be found in general and specialized programs. If hospital admission is required, some SE-AN patients prefer the structure and expertise of a specialist service because there are clear protocols (for example, around meal times) and there is familiarity with eating disorders among all staff members. Such an environment specializing in treating eating disorder patients may feel safer, more predictable, and less stigmatizing for some SE-AN patients.

A drawback of specialist treatment is that it can be tempting to set ambitious recovery-oriented goals that the patient is not ready for and prolong the length of the admission. When there are mismatches between patient motivation and treatment expectations, patients may refuse treatment or misrepresent their recovery behavior in an effort to please. Such clinical situations are typically associated with relapse following discharge.
When an SE-AN patient requires inpatient care due to low weight, medical or psychiatric complications, a general service can be effective. General service admissions work best when there are protocols in place around eating and compensatory behavior, ideally with consultation support from a clinician (i.e., dietician, medical internist) experienced in working with eating disorders. It is also essential for the entire care team to be familiar with and consistently implementing a previously agreed upon treatment plan.

The success of an inpatient admission is largely influenced by the extent to which patients are prepared for and have agreed to the goals of admission. This ideally involves outpatient care providers being informed about the treatment plan and the patient participating in decision-making and having choices. For instance, there could be the option to follow a meal plan 100% or to replace missed items with a meal supplement. Good communication between the inpatient and outpatient care providers regarding what to expect while in hospital is key, whether in a general or specialist setting.

A disadvantage of a general service is that less familiarity with eating disorders and the challenges that eating disorder patients face may lead some staff to use unhelpful labels such as “difficult” or “treatment resistant.” As noted earlier, this may lead to patients feeling judged or stigmatized and erodes therapeutic alliance.

In outpatient general settings, care providers may be reluctant to take SE-AN patients due to fear of medical instability or the belief that they lack necessary expertise. There is a myth or misperception that community services for SE-AN patients need to offer eating disorder-specific treatment in order to be effective. However, current models of care, with their focus on improving overall quality of life while not exclusively focusing on eating disorder symptoms, suggest that general services that are familiar with psychosocial rehabilitation, motivational interviewing, and harm reduction may be well equipped to treat SE-AN patients.

Our experience is that general programs are more willing to accept SE-AN patients when they are provided with support and guidance (for example, consultation, teleconferencing) from specialist services. They benefit from assistance in setting realistic goals and in treating medical complications. Partnerships with specialist care teams increase the comfort and confidence of general services to accept such patients and thereby result in more services for eating disorder patients.

An issue that often arises is how long to work with SE-AN patients, particularly those who indicate that they are not ready to work on full eating disorder recovery. In one of our programs (in Vancouver, British Columbia) a stated motivation for full recovery is not a requirement for ongoing access to outpatient services. However, in that program, patients’ willingness to work toward collaboratively established goals with their care provider was regularly assessed. If patients were no longer interested
in goal-setting they would be discharged with the option to return at a later date. This matching of service provision in response to patient motivation ensured that the service was used efficiently and available for those most likely to benefit. In services where resources are limited, and it is therefore not realistic to treat every client until the point of full recovery, we would encourage consideration of useable boundaries around length of treatment.

Different Models of Care for SE-AN Clients

Thus far, a number of challenges to working with SE-AN clients have been outlined. In responding to these challenges, practitioners and service managers need to think creatively in designing treatment options for SE-AN clients. The issue of “who should treat,” “when” and “in what way” is central to developing creative treatment options. We are aware of a number of treatment models developed specifically with SE-AN clients in mind, and these will be described further. The overarching aim of each of these treatment models is to provide specialist care that is matched to the motivational stage and the needs of SE-AN clients.

Throughout this book, the stance taken is that offering treatment aimed at full recovery is likely to lead to an increased sense of frustration and failure for both client and clinician. Mismatching treatment will only serve to increase client dropout rates and clinician burnout rates. The approaches outlined are designed to share responsibility, meet client need, and hold SE-AN clients safely within a resource limited team.

We would stress the importance of clinicians viewing these treatment models as “stages of care.” Preventing clients from moving through these stages towards other treatment options as their physical health and motivational stage improves will only serve to maintain chronicity. It remains an essential task of every clinician to hold hope for even the most challenging client.

Medical Clinic/Medical Monitoring

A medical clinic describes the allocation of a specified day or date during which SE-AN clients can be seen solely to monitor physical health. A 20-minute time slot is probably sufficient to carry out most of the essential medical monitoring procedures (bloods, blood pressure, ECG, weighing, etc.). A brief questionnaire regarding relevant or important behavior may also be given during or just prior to this time slot in order to obtain essential information regarding frequency of risky behavior.

A medical clinic may be run by qualified mental health nurses, physicians, or a combination of both. Medical clinics should not be the responsibility of a single clinician but should alternate between a number of qualified clinicians.
Managing Severe and Enduring Anorexia Nervosa

The benefits of a medical clinic are that medical safety is kept outside of other interventions that may be currently ongoing, preventing it from interfering with other treatment goals. Medical clinics reinforce the importance of medical stability and give services the option of ensuring safety without offering an active weekly therapy where this cannot be utilized. Where medical clinics are run by a number of clinicians who each share responsibility for running the clinic, the burden and responsibility for SE-AN clients is shared among the team. Additionally, decisions to increase or reduce intensity of care according to medical need are not left solely to the one practitioner who may be attempting to develop and maintain a healthy therapeutic alliance in which psychosocial progress can be made.

Psychosocial Rehabilitation/Assertive Outreach

A small minority of patients with SE-AN may enter psychosocial rehabilitation, commonly taking the form of a house with approximately eight–ten residents, supported by staff. Placements may be up to 18 months and focus on enabling the individual to develop a more purposeful life whilst managing eating disorder symptoms. Residents may learn activities of daily living skills including shopping and preparing food and budgeting, alongside exploring social and occupational opportunities. In our experience, such placements are often only considered after an individual has exhausted all other treatment options.

Assertive outreach may be conducted by a member of the team from any professional background as long as appropriate training in eating disorders and appropriate clinical supervision is provided. In our services we have utilized occupational therapists, health care assistants, and psychology assistants, all under the supervision of more qualified staff. It is crucial that the role of these clinicians is clear, that the goals of working with each client are clear, and that the responsibility for each client is held by a team and never by the outreach worker alone. Examples of tasks undertaken by assertive outreach workers may be to visit a client’s home to assist with meal preparation, to assist with food shopping, or to engage a client in supported eating. Goals centered on improved quality of life may be equally important in these approaches.

Psychological Treatment Options

Psychological interventions can often be underutilized in the treatment of SE-AN clients. There is a belief that we see communicated quite often between professionals, and even to clients, that SE-AN clients are not able to use psychological therapy. We would challenge this view and argue that psychological interventions are almost always appropriate for SE-AN clients. That said, the aim of these interventions, the type of intervention
delivered, and the boundaries of these interventions must be agreed prior to treatment commencing. A previous trial (Touyz et al., 2013) has shown that at least two very different forms of psychological intervention (cognitive behavioral therapy and specialist supportive clinical management) can be beneficial for SE-AN clients in promoting weight gain and in enhancing quality of life. The most important adaptation in delivering psychological interventions to SE-AN clients is that the motivational stage of the client is used to inform goals of treatment. Psychosocial goals, rather than medical goals, are appropriate, as are harm-reduction informed goals rather than full recovery goals; for example, weight maintenance rather than weight recovery, or reduction rather than cessation of compensatory behavior.

**SE-AN Specific Programmes within Day Hospital Treatment**

Placing an individual with SE-AN who has little motivation for full recovery into a traditional recovery-focused day unit is likely to result in a number of challenges for the staff team, the individual with SE-AN, and the other clients attending the day unit. Rather than integrating SE-AN clients into recovery-focused day units, we recommend separate SE-AN clinics be developed with individualized goals and treatment interventions. There are few good descriptions of SE-AN-specific day units within the eating disorder literature; however, we know that these do happen. The overall goals of an SE-AN-specific day program, might be harm reduction, improved quality of life, achieving stabilization, or reducing medical risk and decreasing crisis hospital dependency. It is important to recognize that where goals are adapted, the amount of time SE-AN clients are required to attend may be reduced. Groups are focused on emotional tolerance and interpersonal effectiveness skills. Occupational therapy is involved to help people to focus on the skills they need to be better able to achieve stabilization in the community. Overall, the approach is characterized by clinical flexibility, creativity, and adaptability.

The aim of a day program should be that individuals either progress to the full recovery program, or are discharged back to community care once stabilization has been achieved.

**Brief Structured Admissions**

Hospital admissions are unquestionably required at certain stages. A criticism of admissions for SE-AN clients is that the goals and aims of the admissions are often unclear, resulting in lengthy, often ineffective hospital admissions. We have previously trialed utilizing very brief hospital admissions (up to 21 days) with the aim being solely to stabilize health and commence appropriate physical health treatment. The conditions under which a medical admission is required should be agreed as early as possible in treatment (and may be based on weight, rate of weight
loss, and certain medical parameters, such as blood electrolyte levels or ECG results). Conditions of discharge should also be agreed at admission. The outpatient clinical team or individual therapist should continue to be involved to whatever degree possible.

These clinical descriptions are examples of a small number of creative approaches to working with SE-AN clients that involve the whole multidisciplinary team. This list is not exhaustive and certainly there are many more creative approaches that we could have described here. We hope to provide clinicians with evidence that treatment can be adapted to better suit SE-AN clients without putting further pressure on team resources.

Professionals and their Role in the Treatment of Individuals with SE-AN

A huge raft of professionals could be involved with individuals with SE-AN, all contributing valuable skills. However, in our experience, a low intensity approach, often with one primary clinician, can enable care to be delivered in a clear and boundaried way. Multiple involvement may lead to the individual feeling overwhelmed, emotionally and practically, through the number of appointments to attend. Over-involvement may also lead to the risk of splitting, particularly if an individual deteriorates and intensification of care needs to be discussed. Some individuals will have been within a service for many years and have worked with a variety of staff in that time—this is beneficial in times of staff absence. As we discuss further, it may be more meaningful to support the individual to extend their network beyond statutory health care services, for example, to voluntary or user-led organizations. This avoids the situation whereby most of an individual’s social contact comes from paid professionals.

At the primary care level, the involvement of the family doctor or General Practitioner (GP) is recommended. The GP may manage the individual by themselves or may be working in conjunction with a specialist eating disorder team. The GP may prescribe medication as well as manage the many physical ailments an individual may have. A GP, who can offer home visits, provides a very useful back-up in situations where an individual is unable to leave their home.

Within the secondary care level, there may be psychologists, counselors, nurses, therapists, psychiatrists, occupational therapists, dieticians, social workers, and outreach workers. It is our belief that any clinician qualified in mental health could work with individuals with SE-AN. Practitioners such as dieticians and social workers can provide a vital role but we do not recommend that they would be the primary clinician, unless they have achieved additional specialized training. When working together, clinicians need to communicate frequently to ensure their stance is consistent. We now consider some of the goals that patients and clinicians may be working on together. It will be evident that while
some clinicians may possess skills that are particularly suited to certain goals, there is overlap.

**Improving Quality of Life**

“Improving quality of life” covers a vast array of themes, including engagement in hobbies and leisure activities, work or education and improving social networks, and all individuals working with patients with SE-AN may find that this is the primary goal of treatment. We hope that reengagement with these pursuits increases motivation to address eating disorder symptoms and improve physical health.

Following a bout of flu, Marjorie’s health deteriorated to the point of requiring admission. The inpatient team discovered how isolated she had been prior to admission and noted how much she enjoyed the company on the ward. Marjorie’s psychologist explored ways of expanding Marjorie’s life on discharge and Marjorie identified that she would like to volunteer one morning a week in the local museum. With support, Marjorie contacted the museum to enquire about their volunteer programme. She joined this and found that as well as giving her a sense of purpose she also enjoyed the increased social interaction it provided.

In many areas there are charities or organizations that require volunteers or offer support in matching an individual with an opportunity that suits them.

**Building Skills in Activities of Daily Living (ADL)**

Individuals may have lost or never learnt many ADL skills, such as shopping, budgeting, and meal preparation. Eating disorder rituals or beliefs may also interfere. Occupational therapists and outreach workers can support individuals to address these issues.

Jenny had many beliefs about making sure her food was “just right.” Going shopping could take all day as she visited shop after shop, looking for the “perfect” item. She would also be overwhelmed by choice and “freeze” at the supermarket, before abandoning shopping altogether.

Jenny and the occupational therapist identified her goals: to reduce the time spent shopping, to reduce anxiety around shopping, and to have some basic recipes she felt confident to use. They explored criteria required to judge food, practiced anxiety management strategies, and set gradual goals in reducing the number of shops visited and overall time spent shopping. An outreach worker supported Jenny on some
shopping trips, reinforcing the strategies agreed with the occupational therapist. Jenny identified four basic recipes which she practiced with the occupational therapist in the ADL kitchen.

Monitoring and Maintaining Physical Health

GPs, physicians, and nurses all play a role in supporting individuals with SE-AN to manage and improve their physical health, ranging from conducting regular physical observations and blood tests to addressing issues such as sexual health, smoking cessation, and general health. Individuals with SE-AN may have been on some medications for many years and regular medication reviews and support to reduce some medication (where advisable) is important. For example, some individuals may be dependent on laxatives and require concerted efforts to help stop usage.

Improving Psychological Well-being

Psychological well-being is a broad concept and all clinicians have a role in supporting this. However, there may be a role for specific psychological therapy as delivered by a psychologist, psychotherapist or other trained staff. This is a decision that requires careful thought. It is not helpful nor a good use of resources to offer psychological input in a blanket manner. It is also unwise to assume that because an individual has SE-AN and has undertaken extensive therapy in the past, future therapy will not work. Sometimes life events or reaching significant birthdays can change an individual’s motivation.

Alice had a long history of anorexia nervosa and severe depression, including a severe suicide attempt which had resulted in long-term physical damage and impaired her daily functioning. She had been in treatment for many years. Alice moved into the area of the local eating disorder service and was referred by her new GP. Following assessment at the service, Alice agreed to undertake cognitive behavior therapy. She engaged extremely well and within a year made a full recovery from anorexia nervosa. Alice reflected that the consequences of her suicide attempt and subsequent rehabilitation had led to a significant shift in her relationship with her eating disorder, allowing her to move towards recovery.

Some patients describe that they are “therapied out” and wish to take a break from the demands of therapy. However, it is useful to let them know that they can always reconsider this decision. Sometimes, it may be the team that needs to take the decision that it is not helpful to offer psychological therapy at that time. It is important that an individual is
actively engaged in therapy, even if the goals they are working towards are small, otherwise there is a risk of collusion and undermining of psychological therapy.

We have written about the ways in which therapy may need to be adapted to best serve this population (Bamford & Mountford, 2011). These include instilling hope for all patients, including those who may not achieve conventional recovery; highlighting the benefits of working towards quality of life-focused goals as well as physical health-related goals. In today’s data driven world, this may mean using a variety of outcomes to measure and define improvements.

Who Else may be Involved?

For some individuals with SE-AN, the family will be highly involved, whether it is parents, siblings, partner, or children. Others, however, may be increasingly isolated from their families. Some patients state that they no longer wish for their families to be involved in their care for a variety of reasons, including guilt, shame, or lack of understanding. Family members may have struggled with watching their relative’s continued illness or feel frustration, guilt, or other emotions. However, family members can be a great source of support and encouragement and clinicians may be able to aid this by supporting and teaching skills to families. An assessment of the carer’s needs may be recommended.

Other organizations such as charities and third-sector organizations provide vital opportunities to broaden life. Individuals may engage in voluntary work, attend their local place of worship, or live in supported accommodation.

What Qualities should an Individual Working with SE-AN Possess?

SE-AN patients typically have a history of unhelpful experiences with care providers in which they may have felt blamed, judged, or stereotyped as “difficult.” In order to establish a working alliance with SE-AN patients, a curious, non-judgmental, and compassionate stance is needed. Motivational interviewing is a useful approach for establishing rapport and validating the patient’s experience. It is essential to not make assumptions and to use words and body language that promote honest discussion about the patient’s wishes, needs, and motivation for change. For instance, conveying pleasure when change occurs and disappointment in the face of setbacks are subtle ways that a care provider may inadvertently discourage patient honesty. It is most helpful for care providers to express curiosity about the patient’s readiness and to maintain an investment in patients’ self-acceptance and sense of autonomy as they navigate through treatment.
A number of clinician qualities are associated with a healthy therapeutic alliance and well-being in working with SE-AN patients. There is agreement that the delivery, or tone and stance used by care providers is as important as what is said. It may be useful to consider four common styles and their associated pitfalls when used with SE-AN patients (Geller et al., 2012).

The “Superman” Style is associated with taking charge and expecting patients to follow directives in order to bring about change. Different tactics are associated with this style, such as being overly directive and trying to scare patients into recovery by telling them about the health consequences of their eating disorder. The primary pitfall of this style is moving too quickly into action and not taking sufficient time to understand the patient’s perspectives and wishes. The Superman Style does not provide patients with choices nor foster autonomy.

The “Cheerleader” Style is associated with cheering for and encouraging change. Care providers with Cheerleader tendencies may find themselves telling their patients how much better they will feel if they engage in treatment and follow a recovery plan. The primary pitfall of this style is failing to recognize what is meaningful to the patient. As a result, although patients may initially enjoy the positive hopeful messages they receive, they may also feel discouraged and afraid of disappointing the therapist if their readiness for change is low. This may lead to a less authentic relationship in which the patient is not forthcoming about their actual symptoms or change behavior.

The “Mr. Nice Guy” Style is associated with a primary focus on minimizing patient distress through support, empathy, and acceptance. The Mr. Nice Guy Style is linked to difficulties setting limits and the absence of clearly stated bottom lines. As a result, although patients typically enjoy their sessions, there is a risk that their health will deteriorate in the absence of a clear safety plan. This may further contribute to patient and care provider distress.

The “By the Book” Style is associated with rigid adherence to a treatment protocol despite evidence that the patient is not benefitting. Thus, the By the Book Style may be likened to trying to fit a square peg into a round hole. Although there are excellent treatment protocols that benefit a great number of individuals, the complexity and readiness issues in SE-AN patients often require use of a more creative and flexible protocol, that is reviewed and tailored regularly.

Despite the pitfalls of these styles, there are also beneficial aspects to each that can be capitalized on in the successful treatment of SE-AN patients. For instance, Superman is needed in setting safety non-negotiables, cheerleaders can help encourage patients on goals that are meaningful to them, Mr. Nice Guy is essential in building rapport, and the By the Book style is necessary for teams in adhering to a consistent treatment plan.
What do Clinicians who Work with these Individuals Think?

We asked clinicians who successfully worked for over a decade with this group in a program specifically developed to treat SE-AN patients, the Community Outreach Partnership Program in Vancouver, British Columbia, to describe key ingredients of their practice. They were also asked to describe what they believed contributed to their resilience and avoidance of burnout. Consistent themes that emerged were: celebrating small victories, tolerating bumps and setbacks, and accepting that the decision to recover is the patient’s, not theirs. They also noted that they were not derailed by relationship challenges such as patient mistrust or silence and were able to remain empathic and curious about the patient’s experience through the ups and downs of treatment. Another key factor that emerged was their acceptance that in many cases full recovery may not occur. Overall, successful clinicians were invested in supporting the patient’s higher values and quality of life over the long term and had faith that this stance was the most productive way of promoting recovery.

Conclusion

This chapter has aimed to explore the question of who should treat, or be involved in treating, clients with SE-AN. We hope to have made it clear that a range of professionals have a role in supporting and treating these clients, and that the most important factor in successful treatment is the ability to work collaboratively, towards shared goals, in an integrative and creative way. We are aware that treatment decisions are often dictated by resource issues. Despite this, and even when resources are limited, effective models of treatment can and should be developed and delivered within both specialist and generic care teams.

References


Managing Severe and Enduring Anorexia Nervosa

Hospital Admissions in Severe and Enduring Anorexia Nervosa
When to Admit, When Not to Admit, and When to Stop Admitting

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The authors acknowledge all those with SE-AN who have allowed us to accompany them on their voyage, and who have shared their thoughts with us.

Individuals with severe and enduring anorexia nervos (SE-AN) suffer a variety of medical complications related to the severity and chronicity of their illness. These complications, which can include the risk of an imminent death, can lead to the consideration of hospitalization at times. While numerous guidelines exist about medical indications for admission, a separate topic is the consideration of how to approach hospitalization in a more global way in the SE-AN group. Hospitalization in this group spans from the collaborative approach described, to involuntary hospitalization, through to the difficult decisions around ending active treatment; they are all part of the same journey, involve the same patients, and need to be considered together.

Yager (1992) provides an approach to the therapeutic stance with such patients that emphasizes warmth, collaboration, and clear goal setting, especially for hospitalizations. Touyz et al. (2013) report seven hospitalizations in the course of their randomized controlled trial for SE-AN but do not comment on the reasons, nor the process for these admissions. The lack of additional literature specifically focusing on hospital admission for SE-AN is a shortfall in the current literature.

This chapter will attempt to start to fill this gap. The first part of the chapter presents our own model, developed in Toronto, for dealing with voluntary hospitalizations for the SE-AN group. Second, we will provide a brief discussion of involuntary admissions, and finally describe our own approach to the decision to forgo further admissions in this group. Because there is so little literature on this topic, this chapter is more in the format of a clinical discussion than a formal academic review: we hope that it will stimulate further discussion in this area. We offer a number
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of clinical case vignettes and examples to illustrate some of the principals that we are describing. This chapter overlaps with Chapters 12 and 14, which also focus on involuntary admissions and palliation.

A Model for Managing Admissions to Hospital for SE-AN: Symptom Interruption (SI)

As the major quaternary care center for SE-AN in Ontario, Canada, the program at Toronto General Hospital tends to attract the very sickest patients with anorexia nervosa (AN). Due to the lack of treatment resources in Ontario, patients with enduring disease tend to remain attached, at various levels of engagement, with our program for years or even for decades. As a publically-funded program, with a fixed budget, it has been important for us to attempt to develop models of care that allow us to get the best “bang for the buck” when we choose to hospitalize a patient with AN.

Our current model for inpatient treatment began to be developed in the late 1990s. As is the case for many involved in providing such treatments, we rapidly realized that our routine treatment—admit to a comprehensive treatment program with the goal of attempting to make a recovery—was not suitable for many of our patients. If it was all that was available, many would try it, often with unhappy results for the patient, and frustration on all sides. In about 2000, we began to think more actively about how we could address the needs of these individuals. We concluded that our experience suggested a number of things:

- Many such patients are pessimistic about the chance of routine treatment being of use to them.
- Many such patients cannot conceive of the possibility of a “recovery.”
- Many such patients are interested in incremental improvements in their eating disorder.
- Many such patients are interested in exploring ways to improve their overall quality of life.
- Many such patients do not wish to die, and are willing to come to hospital under certain circumstances to improve their overall condition.

In other words, although such individuals may not have our view of “recovery” as a goal, or something they are striving for, they can articulate ways in which they are interested in improving their lives overall, or maintaining their overall health status.

Funding for our program is provided as a protected grant from the Ontario provincial government to our hospital. These funds are ring-fenced and may not be used for another purpose: and as a consequence, the hospital will not invest any further funds in the program. Due to the nature of our health insurance plan, while hospital based care is provided essentially free of charge, private care is illegal and it is not possible to
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raise any additional funding for our program directly from patients. We are thus in a condition of scarcity, typically with significant waiting lists for our treatments.

This produced a dilemma when considering how to address the needs of the SE-AN group. With a set funding envelope, a fixed number of beds, and a substantial waiting list of individuals who are willing to attempt to become fully weight restored, we needed to consider how to prioritize the SE-AN group who have much more limited goals. With our fixed envelope of resources, every time we admit one such person, an individual who wishes to attempt to make a full recovery has their admission delayed.

One alteration in our ability to provide some services to this population came about as a consequence of some changes made in our treatment in the late 1990s. Our funding envelope does not allow for a step-down facility as is common in many programs around the world, and although we do have a day hospital (DH) service, the mandate of that service is to treat more severely ill patients with bulimia nervosa (BN), with a long waiting list. We had made an attempt to transfer patients from our inpatient service (IP) to the DH in the early 1990s, and then again more recently, and found this to be unsatisfactory as patients did not tolerate changing clinical streams well, and the practice also extended the DH waiting list to an unreasonable degree.

In the context of some additional funding, we implemented a plan to allow for resident inpatients to switch to continuing to attend our IP service during the day once they had made sufficient progress, typically at 8–10 weeks after admission. Our average BMI at admission is 13.5. Given the group nature of the program, the incremental cost for such patients is minimal. As a group program, we wished to cap the size of the group at 12, and this meant that when we had more than two of our IP patients attending during the day, we would have empty beds that we could use for admitting patients, such as the SE-AN group, without increasing the length of the IP waiting list.

We called this part of our IP service “symptom interruption,” or SI, and have been admitting patients in this fashion since 2001. The exact details of the staffing model have varied over time, depending on the ebb and flow of our funding, but the core principles have remained the same, as described here.

Core Principles of Symptom Interruption

Meet the Patient Where She Is

In most full treatment programs, the program is presented to a potential patient with a host of goals embedded within a program structure. The patient makes a decision to endorse those embedded goals when she chooses to enter the program.
In SI, the process starts with a blank piece of paper on which the clinician and patient develop a set of goals and a plan to achieve them. There are no preconceived notions, aside from the goals being realistic for the setting. Any goals, so long as they are consistent with the maintenance or improvement of health, can be appropriate for SI. There are no minimum standards. For example:

Zoe has had AN for over 20 years. She has no specific interest in recovery-focused treatment, but does not wish to die from her illness. Her initial contact centers around her belief that her physical situation is deteriorating and that she wishes to try to stabilize her situation.

Yvette has had serious ANBN for 15 years, and has had numerous episodes of treatment. She is uncertain as to how to proceed and her initial contact is focused on “clearing my head” from the chaos of starvation, bingeing, and purging to try to decide about what her next step might be.

Wanda, who has been ill for 12 years with AN, has run into a wall in terms of her ability to complete her schooling. Her initial contact suggests that she is aware that for her to be able to complete school, she will need to gain some weight, perhaps 10lbs. She is uninterested in complete weight restoration. An additional feature of her situation is that she has had a deep brain stimulation (DBS) device that appears to have lost its effect.

Veronica has had difficult experiences in the group setting, where her post-traumatic stress disorder (PTSD) has made it difficult for her to be present and attentive in the group. Her frequent flashbacks and episodes of being triggered have been embarrassing for her and distressing for the group in the past. Her initial contact revolves around options for treatment, and she is focused on a complete recovery.

**Goal Setting as a Collaborative Process**

Goal setting in this process is driven by the patient, with input from the clinician, and is focused on the ability of the setting to assist the patient in working on specific goals.

The clinician will have an important role in assisting the patient to frame her goals in a way that makes sense to both the patient and the clinician. For example, a patient who wishes to gain a limited amount of weight and yet at the same time have passes off the ward for hours each day to walk is setting unreasonable conditions on her admission that will prevent her from achieving her stated goal. This will need to be respectfully discussed with the patient.

This process is reminiscent of a mixture of motivational interviewing and psychoeducation. Clinicians negotiating such goals must have a patient and non-judgmental attitude. The clinician can be authoritative,
that is, function as an expert in AN, but not authoritarian, and must be very careful to respect the autonomy of the patient.

**Defining End Points of Treatment, Success, and Outcome**

Contracting should include explicit descriptions of how the end of the treatment will be decided, what extensions might be available, and what alternate treatments might be utilized depending on the outcome of the treatment. These elements of the contract will define the outcome, at least from the perspective of the patient. Referring to the case vignettes above:

Zoe, who is focused on medical stabilization to revert some deterioration, is unsure of what this process could look like. The clinician first elicits a list of things that concern Zoe. She identifies that she feels weaker overall, and is having some difficulty climbing the one set of stairs in her home. She is no longer able to walk the family dog. She has been trying to do a distance course over the internet and she is finding it increasingly difficult to concentrate on her schoolwork. She has noticed that her daily caloric intake has dropped from about 800 kcal/day to about 500 kcal/day, and is unsure of why this is. Her weight has declined slightly from a BMI of 12 to a BMI of 11.5. She is very clear that she does not view herself as either terminal or suitable for palliation, and that she wishes to “feel better.”

The clinician initially asks her why she thinks her condition has worsened. She is able to acknowledge that her caloric intake is reduced, but is unsure of how this integrates with her perception that her activity is also reduced. She admits to a terror of eating more, or of gaining any significant amount of weight, and at the same time has some recognition that this is necessary.

The clinician takes some time to gently review energy balance issues with Zoe, and asks her whether she is ready to get into a positive energy balance, if that is what it will take for her to feel better. A lengthy discussion ensues, where Zoe wonders if she actually needs to get into a positive energy balance, or whether she just needs to “stabilize” and not be negative any more. The clinician indicates that in his experience, it might be very difficult for her to regain any functional capacity without some positive movement, that trying to balance where she is now might prevent further deterioration, but perhaps not improve matters much.

Zoe needs some time to mull this over so they arrange to talk again later that week. At the next meeting, Zoe says that she thinks he is right, and that she does need to make some small changes that might return her to her previous stable state. She then expresses significant concerns about how this would have to happen, what she would have to eat, and the extent to which she would need to be externally constrained for this to happen.

The clinician asks her what changes she thinks she would need to make to her eating to be more functional. She is able to acknowledge that she might well need to return to her previous level of 800 kcal/day, but is
worried that she will be made to eat foods that she would find difficult to tolerate in hospital. The clinician reassures her that she will be free to choose from the program menu whatever foods she finds most tolerable, within the bounds of what is available, as long as she is able to make her daily caloric goal. He asks her how she would like to be accountable for eating this food—noting that there is not much point in coming to hospital if she is not able to eat the food—and she agrees to eat the food in her room and to have tray checks by nursing staff, and to be supplemented for anything she is not able to eat. They negotiate a time limit of one hour per meal, to avoid Zoe having food in her shared room when other eating disordered patients have returned from their own meals. She is able to understand how this might be triggering for them and does not wish to disturb them.

Zoe then asks about passes off the ward. The clinician asks her what she thinks is reasonable given her goals for her admission, and reminds her of the metabolic effect of even moderate amounts of physical activity in the context of refeeding. This frightens Zoe, although she has some ability to understand that if she is burning off calories then she will have to eat more to strengthen herself. After some discussion, she agrees to have three short passes off the ward daily to get coffee, and to reassess this regularly. The clinician suggests an initial trial of two weeks to see how Zoe is responding, with an option to continue and possibly set new goals at the end of that time. They discuss what staff time will be available to Zoe—most of which will be used for psychoeducation and reassurance—and also decide that she will not be weighed for the initial two-week period as she expects to have a jump in her weight due to a resolution of her dehydration.

The final discussion point relates to her non-psychiatric medical care. The clinician notes that if there are unexpected medical events, such as profound dehydration or cardiac instability, she might require some medical interventions, including the possibility of an intravenous line. Zoe is adamantly against any such intervention. The clinician gently reminds Zoe that the goal is to have the least intrusive intervention possible, but that if her medical situation is unstable, then the attending physician would need to flexibility to attend to that while keeping her informed, and with her consent. The clinician further reminds Zoe that one of her goals at present is to not die, and that if the attending physician was concerned about that, it would make sense for her to allow a life-saving intervention.

Yvette has difficulty in elucidating treatment goals, due to the severe effects of starvation, bingeing, and purging on her cognitive capacity. The clinician patiently tries to help her understand that part of her problem in thinking clearly is related to her very starved state. She eventually is able to agree that until there is at least minimal change, she will be unable to make any decisions about how to proceed with her treatment in the future. The clinician suggests that one useful thing that Yvette could accomplish in a week or two would be to “take a break” from her bingeing and
Yvette is ambivalent about eating anything if she is not purging, and terrified about any weight gain given the likelihood that she will suffer water retention. The clinician reviews her past treatment history with her, and suggests that this shows that weight gain has been very difficult to generate. The clinician further suggests that if Yvette is able to eat even a small amount of food, it will assist her in achieving her goal of being able to think more clearly about her future. Yvette asks if she will have the option to choose freely from the hospital menu, and the clinician tells her that the dietitian will meet with her to help mark her menus, but there will be no enforced eating. They agree on a two-week admission.

Wanda, like Yvette, is very starved and is functioning at a low level. An initial conversation very similar to that with Yvette ensues, where the clinician asks Wanda to talk about when she has felt that she has functioned the best. She is able to identify that the six months after the DBS surgery were good months for her. She is further able to note that since that time her activity level has gone up significantly, with her running having increased from 30–60 mins/day, and that her food intake has marginally decreased, all because of the stress of school. The clinician reviews the available information about the DBS device, which suggests that there is a net caloric “floor” to allow it to have an effect, and that it would take about three weeks for that to be apparent. Wanda is eager to regain the effect, which included much better moods, less anxiety, and improved OCD symptoms, and agrees to eat 1200 kcal/day and restrict herself to brief passes off the ward to contain her activity. They agree on a three-week admission.

Goals may be modified over the course of an admission:

Veronica is desperate to see significant improvement in her overall condition. She is aware that she cannot cope in the group setting of the regular program. The clinician asks her how she thinks she might do with minimal meal supervision, and daily support from staff at a low level focused on helping her maintain the effort of meal completion, and working on affect tolerance skills for her PTSD. She is ambivalent about this as she does enjoy the support of other group members but is also fearful of making things more difficult for them. She is otherwise agreeable to “do the program” with individual support from staff and see how far she can go. She has few concerns about the nature of the food or the process of weight gain itself.
Staff work intensively with her after she is admitted to develop more effective affect tolerance skills. A trial of a medication used to decrease nightmares in PTSD is started, and she is informed about an investigational treatment for PTSD that she considers. She opts to attend some educational sessions that are available both to the main patient group, and to SI patients.

After three weeks, she feels settled enough to consider eating with the main group of patients, and to have additional support. Her nightmares are significantly decreased, she is making good use of her grounding and affect tolerance skills, and has been referred for the investigational treatment, which will last three weeks.

She tolerates eating with the main patient group well. They tolerate her occasional episodes of dissociation and are very supportive. This gives her more confidence that she is actually making progress in her treatment.

By week seven, having gained about half the weight she needs to gain, she has completed her course of investigational treatment and finds that her PTSD symptoms are much reduced. She has an excellent working relationship with her individual trauma therapist, and is very comfortable at supervised meals. She asks if it is possible for her to have a trial of treatment in the main program. Although she finds this challenging, the overall reduction in her PTSD symptoms allows for her to manage, and she is able to complete her treatment within the main program.

Formally Assessing Outcomes of SI

The wide range of treatment plans negotiated with SE-AN patients makes it difficult to offer specific formal outcome measurements for our SI program. Our narrative feedback suggests that most patients have found their admissions helpful, but the definition of “helpful” is not very precise. Perhaps the best thing that we can report is that many such patients will have a succession of SI admissions, which suggests that they view the experience as positive. Clinically this model does appear to have utility with the SE-AN group.

Although the previous description of our collaborative SI approach may seem positive and encouraging, the other side of hospitalizations in this patient group is much more difficult and presents special challenges for patients, families, and clinicians alike. Unfortunately, despite all efforts to the contrary, patients with SE-AN will be faced with the possibility of deterioration to the point where an involuntary admission might be required, or their condition will progress to the point where there appears to be no hope. We consider it important for clinicians to maintain a hopeful stance toward individuals who find themselves in these situations. It is equally important for clinicians to be able to clearly assess the state of such a patient, and to be able to be honest and forthright in a kind and compassionate way.
Capacity, Consent, Involuntary Admissions and Decisions to Halt Treatment and Management

Capacity and Consent

The ability to consent to treatment is a fundamental tenet of most health care systems. A full discussion of issues surrounding capacity and consent to treatment in severe AN is outside of the scope of this chapter. There is little literature which focuses directly on this issue. For the purposes of the remainder of this discussion, we will assume that the patient with SE-AN is competent to consent to treatment in almost all of the situations discussed. We are aware that this is an oversimplification. However, the model presented, of long-term collaborative work with SE-AN patients, does presume capacity under most circumstances.

Involuntary Admissions

As this topic is covered separately in Chapter 12, it will be mentioned only briefly here. The need for an involuntary admission needs to be carefully considered in this population. In our setting, all “treatment” is voluntary and we frame involuntary refeeding as “management.” We do not generally consider that management will generate ongoing change, as it is implemented simply to rescue the patient in the moment from something that will imminently kill them.

If we are working from the framework of SE-AN, which primarily involves a collaborative relationship with the patient, the first priority is to have a discussion with the patient in question about their wishes. In this case, the discussion is no different from the discussion one might have with any patient about end of life care or advance directives.

The clinician should have a frank discussion with such patients about their wishes. The clinician should be explicit about their typical criteria for involuntary admission, and what such admissions look like. We find it helpful to reassure patients that such admissions are to be brief, as non-intrusive as possible, and respectful of the patients’ advance directives.

Most patients indicate that they do wish to be admitted if the alternative is imminent death. Such a discussion about an involuntary admission often helps the patient to feel less disempowered, and actually can strengthen the therapeutic relationship with the patient.

It should be made clear that such a discussion is not meant to diminish or substitute the clinician’s responsibility for making a determination that death is imminent, or to prescribe appropriate management to try to prevent such a death, if either the patient has indicated that she wishes death to be avoided, or there are other circumstances in which the clinician’s opinion is that death should be prevented. There should be a compelling reason to intervene when a competent patient has clearly indicated a wish to avoid further life-extending interventions.
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Decisions to Withhold Further Active Treatment and not Admit in the Future

There are no guidelines, research, nor little discussion, about the decision to halt active treatment and management in the most severely affected individuals with SE-AN. There is no available scientific evidence which can predict who is likely to recover and who is likely to have a chronic, intractable course, despite all efforts at treatment. Any clinician working with such patients will be able to relate stories of how patients who appeared to be totally without any chance of recovery eventually did so, and how other patients who appeared to have excellent prognoses had a premature death. There is an urgent need for more research in this area. Clinicians are left to their own best judgment as to how to proceed. We provide some commentary on this issue from our own experience working with such patients, in the hope that it will generate further discussion on this important topic.

This discussion does not involve those patients who acknowledge they are dying and ask for palliation. In our experience, this is a very small group of those who have SE-AN. That topic is covered in Chapter 14. Rather, this discussion is focused on those individuals who appear to be close to death, have no clear sense that they are at risk of death, are uninterested in routine treatment, and who might otherwise be candidates for involuntary admission.

In this discussion there are multiple interests that need to be considered. First and foremost, the interest of the patient is the primary determining factor for patients being deemed as competent to make treatment decisions. The interest of the family may also need to be considered, as is the case in most illnesses that could be mortal.

The experience and outlook of the clinician involved is also relevant. For many in the field, we have seen those ill for decades make miraculous recoveries, and the very young suffer from seemingly malignant disease and perish early in the course of their illness. In our opinion, an important role for those engaged with this population is the maintenance of a hopeful stance about recovery or improvement, even in the face of long-standing or very severe illness. This then must be tempered by the recognition that a significant percentage of those affected with AN will die from their condition despite all efforts. As noted by Yager (1992), clinicians involved in the care of such patients must be prepared to engage with a wide range of responses: hostility, indifference, hopelessness, and apathy. An internal response of anger toward the patient is never helpful.

In the absence of much scientific literature, we tend to be conservative in the first 20 years’ duration of illness. Although recoveries appear to be less common after 10–15 years’ duration of illness, they still certainly occur. A patient with an average duration of illness of 15 years is typically around 30 years of age. Neither the patient nor the family is prepared to
abandon hope for an individual at that age, even in the face of relentless illness and lack of interest on the part of the patient to seek out any form of treatment. We routinely advise for involuntary management when death is imminent until approximately 20 years’ duration of illness, which typically places the patient in her mid- to late 30s. We further believe that any patient with severe AN should have at least one involuntary admission, if required, and that no such patient should be allowed to die if they have never had an involuntary admission in the past.

There is no literature describing the natural history of the condition, or what heralds the terminal phase of the condition. In our experience, the illness tends to have three phases. The initial phase, lasting 1–2 years, is typically marked by extreme medical instability and often very low weights. The instability is related to the body trying to adapt to a situation of chronic starvation. There appears to have been an increase of deaths in this phase of the illness. We believe more aggressive treatment, especially of adolescents, may have reduced the death rate early in the condition.

The middle phase of the illness, the “stable sick” phase, will last a variable length of time, as short as ten and as long as 30 years, and is characterized by the patient having reasonably stable weight at a low level, and some level of functioning in their life. While death can occur in this phase of the illness, in our experience it usually does so as an “accident” related to transient medical instability or comorbidity such as severe depression, rather than being the consequence of low weight.

The hallmark of the third, or, terminal, phase of the illness, is the return of medical instability, including unexpected and non-deliberate weight loss after this long period of stability. In our experience, this final phase lasts 2–5 years, and it is not possible to return the patient to a “stable sick” condition. The patient must make a final effort to substantially recover, or perish from the condition.

We are not inclined to deny life-saving management, or offer palliation to an individual in the first two phases of the illness. We are of the opinion that maintaining a hopeful stance about eventual improvements is the most appropriate clinical stance for such patients. Most such patients will indicate that while they would not willingly ask for involuntary management they do not wish to die, and will agree, perhaps grudgingly, that an involuntary intervention had been in their best interest.

When it appears that the patient is entering the terminal phase of the illness, we prefer to have an open discussion with the patient and the family about the apparent course of the illness, and the likely prognosis and options. We find it helpful to be kind, compassionate, and patient, with the patient and with the family. Patients who are in their late 30s or older tend to be able to understand what is happening to them and to engage in a useful discussion about how to proceed. Younger patients, those in their late 20s or early 30s, who have had a
shorter “stable sick” period, tend to have more difficulty in engaging in such discussions.

We will outline the most likely prognosis at this point: a premature death. At the same time we note that a substantial or total recovery does remain a possibility, even if an unlikely one. We then seek guidance from the patient, and, if involved, the family, as to how to proceed.

The response of patients in this situation is variable. Many patients have been aware on some level that their condition has been deteriorating. Often the discussion has started because the patient has requested an appointment for a reassessment, being aware of changes in her condition. Other patients require more than one meeting, and some time, to decide about the information that has been provided. Very few patients are totally unable to grasp that their condition has changed in a negative way.

Many patients in this group express a willingness to continue to engage in treatment or management of one type or another. A substantial minority re-enter treatment, and some do quite well. Others will opt for experimental treatments. An example of this is our deep brain stimulation trial (Lipsman et al., 2013), which involves the neurosurgical implantation of electrodes in the deep structures of the brain, with ongoing stimulation from a pacemaker-like device implanted in the chest. When we started this trial in 2011, we were unsure as to whether there would be interest: at the time of writing, 19 patients have entered the trial, and there are four on our waiting list. In contrast, for the initial trial in depression, it took over two years to recruit the first six patients.

Decisions like this, which may seem born out of desperation, in our view suggest that many such end-phase patients actually have not entirely lost hope that something might improve in their life. They may be profoundly pessimistic that what we usually have to offer will help them. This may represent reasonable insight, after three, or five, or ten failed attempts at routine treatment. It is worth thinking carefully about the nature of hopefulness versus despair in such patients, and the role of the clinician in dealing with both.

In our experience, there is a small group of patients who will make a clear decision that they simply wish to be left alone, and that they do not wish any interventions of any type. One way in which such decisions present is by the patient simply disappearing and not engaging with clinicians of any discipline. In rare cases, such patients may wish to continue to meet with clinicians, for emotional support or advice about managing their terminal illness.

When patients decide that they wish no further intervention, families may disagree with this decision. This can be an extremely difficult situation to manage. We recommend making the best effort possible—perhaps over a significant period of time—to bring the patient and the family together to make decisions about what will and what will not be done. Such meetings can be highly charged, and some families will simply
not agree to give up. The involvement of other specialists can be helpful, as described in this case example:

Ursula, aged 32, was admitted through the emergency department of a major teaching hospital. Ill for 18 years, she had a long history of laxative and diuretic abuse, which had compromised her renal function. Her weight was low, at a BMI of about 14. She presented with unexpected heart failure, and a very low cardiac output, compatible with a need for heart transplantation. There was no obvious cause for this cardiac decompensation. She was managed for her heart failure for several months in the expectation that her cardiac function would gradually improve. However, this did not occur, and she eventually became trapped between out-of-control heart failure, and renal failure secondary to her pre-existing compromised renal function, and the adverse effects of the diuretics required to manage her heart failure.

It became clear that her prognosis was poor, there was little chance of a recovery, and that her lifespan was limited to a few months at best. She was deemed not to be a candidate for a heart transplant because of her poor renal function and her chronic AN, and not suitable for a kidney transplant because of her compromised cardiac function. The possibility of a dual transplant was ruled out because of her extremely low weight and overall debilitated condition. The senior author and cardiologist met with her and presented the situation to her. While distressed, she was able to understand her situation and requested that all active treatment be discontinued and that she be made as comfortable as possible.

Her family was very strongly opposed to this decision, and was very desperate and distressed. The patient agreed to postpone her decision to end all active treatment so that we could try to work with her family to help them come to some acceptance of her situation and her decision. A series of joint meetings were held with her entire family, the senior author, and cardiology staff to review all the information available, treatment options, her prognosis, and the likely short duration of her survival. With great difficulty, and terrible distress, her family was eventually able to accept that since there was no hope of a recovery, it was a reasonable decision for the patient to discontinue all active treatment. She did so, and died ten days later. Some months later, in a meeting with her former roommate, who also had AN, this individual revealed that the original patient had been using ipecac chronically, thus explaining the presentation with heart failure and the lack of any improvement.

Conflicts of this nature will often present in the emergency department, where a very ill individual is protesting against an intervention of some type, while the family is insisting that the patient be managed, or resuscitated. Clinicians will need to respect the legal framework around such situations in their own jurisdiction. In Ontario, in the absence of
a written advance directive, a patient who is unconscious or unable to communicate is likely to be resuscitated if any family member insists. It is always best to make every effort to bring the family and the patient together outside of the context of the highly-charged environment of the emergency department.

Once a clear decision is made to withhold further active treatment, the patient may express a wish for palliative care of some type. This is covered in Chapter 14.

Conclusion

There is no question that the care of patients with SE-AN will require the possibility of hospitalizations from time to time. Ranging from the possibility of collaborative admissions, through to involuntary admissions, and the consideration of the cessation of hospital based interventions, the role of the clinician is to make every effort to engage the patient in an understanding, non-judgmental relationship that seeks to enhance quality of life, and to maintain hope in those cases where the patient and her family have lost hope.

There is an urgent need for increased dialogue about the issues raised in this chapter. The potential for miscommunication and adverse results from hospitalizations is extreme. The worst outcome of such is the possibility that patients who feel misunderstood or traumatized by well-meaning interventions may either lose hope or lose trust in the health care system and be deprived of potentially useful care. There is a further need for research into what outcomes occur in these individuals, and how these are perceived by the health care system and by the patients themselves and their families.

References


Contemplating suitable circumstances and justifications for the involuntary treatment of severe and enduring anorexia nervosa (SE-AN) presents numerous challenges. Although there is considerable support for resorting to civil committal powers to coerce selected SE-AN patients into treatment (Bowers, 2014), there is ongoing debate about the characteristics of the group for whom this is justified, and about when a patient should be permitted to decline treatment where refusal is likely to result in their death (Gans & Gunn, 2013; Giordano, 2010; Lopez, Yager & Feinstein, 2010).

International approaches span a wide range of clinical, ethical, and legal positions (Carney et al., 2006). In federations, such as the United States, Canada, or Australia, legal and clinical responses can vary from one part of the country to another due to policy choices by clinicians about the use of the law, and because the constitutional authority to make laws lies with the states or provinces, rather than the central government, enabling different approaches to be taken from one jurisdiction to the next. In Australia for instance, some jurisdictions (such as Victoria) rely on mental health (civil commitment) laws alone, while in the neighboring jurisdiction of New South Wales the more “empowering” philosophy of adult guardianship (with its interposition of a guardian between patient and clinician) is open to be used as an alternative to mental health laws (and even child protection laws have been utilized) (Carney et al., 2003). Mental health laws also differ among themselves (some favor empowering clinicians to invoke coercion subject to later review, others insist on prior approval of a legal body: Carney et al., 2011) and differ between countries in whether courts (as in the United States and much of Canada) or multi-disciplinary tribunals authorize or review the exercise of coercive powers (as is the case in Britain and Australia), as well as in whether involuntary detention grants authority to impose treatments such as medications (as in Australia), or requires separate legal authorization.
This chapter explores the often vexed and complex dilemmas confronting the clinician when having to decide upon the involuntary treatment of a patient with SE-AN. It explores the literature beyond the evidence base. It then provides some considered wisdom, extracted from the published literature, to guide the clinician through what often can become an emotionally-charged encounter with an oppositional patient. Clear decision-making based upon sound clinical principles can often pave the way for a more successful outcome without what many would consider a “bruising battle” of wills. Finally, the road ahead is addressed looking at compulsory treatment from an international perspective and briefly touching upon the urgent need for research to determine whether such patients do have the mental capacity to make such potentially life-saving decisions.

An Evidence-Based Justification for Involuntary Treatment of SE-AN?

The meager evidence that exists to help guide clinical decisions is based on poor quality studies. The literature is limited to several case series that compare relatively small numbers of patients hospitalized involuntarily with voluntary patients seen in the same facilities over similar periods of time. Optimistically, they show that short-term weight restoration outcomes for patients subject to compulsory hospitalizations are comparable to those hospitalized on a voluntary basis. For the most part these series are buttressed by anecdotes underscoring the fact that some of the patients were “saved” and “turned around” by being placed on involuntary treatment. However, where follow-up data is available they also show that longer-term outcomes for those hospitalized involuntarily are considerably worse than for voluntary patients, not surprising given that involuntary patients are often sicker, have greater comorbidities, and are almost always less motivated to seek care after discharge from compulsory hospital treatment. Although anecdotal cases also circulate describing patients who die despite being placed into involuntary treatment, few of these cases appear in print, again not surprising, given that few clinicians are willing to publish what they and others might perceive to be treatment failures. Although numerous discussions of various legal, moral, ethical, and clinical issues are available, only a few data-based studies provide possible guidance.

Ramsay and colleagues (Ramsay et al., 1999) reported on 81 patients admitted to the Eating Disorders Unit at the Maudsley Hospital under Britain’s Mental Health Act for compulsory treatment (16% of all admissions to the unit). Before their index admission, seven had been previously involuntarily admitted once, four detained twice, three detained three times, and one four times. These involuntary patients were paired and compared with 81 patients admitted voluntarily during
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the same time periods. Admission data on patients admitted on involuntary compared with voluntary status included numerous measures on which the two groups did not differ significantly, for example, respectively, average ages were 26.2 and 25.4 years, mean length of illness 8.2 and 7.6 years; mean admission BMI 14.2 and 14.3, history of binge eating 40.7% and 44.4%, purging 50.6% and 44.4%, and comorbidity 44.4% and 30.9%. Statistically significant differences were seen, respectively, for childhood physical or sexual abuse (24.1% and 10.1%), histories of self-harm (59.3% and 33.3%), and number of previous admissions (mean 3.3 and 1.8). Notably, the length of admission was significantly longer for the involuntary patient group (mean 113 days and 88 days), but the discharge BMIs were very similar (mean 18.7 and 18.5), showing that with some effort, comparable short-term outcomes could be achieved, at least with respect to weight restoration. At an average follow-up of 5.7 years, data was obtained from the National Health Service Registry on patients in this group who had died and their causes of death. At follow-up, 12.7% of the involuntary group had died (10 of 79 for whom data were available), compared with only 2.6% of the voluntary group; discouraging, but not surprising. One death in the involuntary group was attributed to “misadventure,” the others were attributed to a variety of cardiac and pulmonary causes and to anorexia nervosa.

In a similar study of 397 patients admitted to an eating disorders unit at the University of Iowa over a period of seven years, 66 (16.6%) of whom were admitted through involuntary legal commitment (60 females and six males), Watson, Bowers & Andersen (2000) also found relatively few clinical differences between voluntary and involuntary admissions. The involuntarily patients averaged 24 years of age, 28 (42%) were diagnosed with anorexia nervosa, 18 (27%) with bulimia nervosa and the remaining 20 (31%) with an eating disorder not otherwise specified (EDNOS). On average, these patients were not as ill as those described in the Ramsay et al. study. The mean length of illness among the involuntary patients was 96.8 weeks (SD 75.8 weeks), average BMI on admission was 17.4, and average BMI at discharge was 20.5. The overwhelming majority had five or fewer previous hospitalizations, but a minority (nine of 386) had ten or more prior hospitalizations. Among the involuntary patients, 47% had comorbid diagnoses of depression and 29% of substance abuse. Although, as in the Ramsay et al. study, involuntary patients required longer hospitalizations than voluntary patients (56.7 compared with 40.6 days), and by discharge averaged greater weight gain than voluntary patients (18.8 pounds compared with 13.9 pounds), their short-term outcomes with regard to weights were comparable, focusing only on the involuntary patients with anorexia nervosa, by discharge their average mean weight compared to matched population control weights was 90.5% and 91.2% for voluntary patients. Anecdotally, the authors note that by the time of discharge many of the involuntary patients acknowledged recognizing
and endorsing the need for treatment. No long-term follow-up data were included in this study.

Although not specifically studying patients admitted on involuntary legal status, the results reported by Guarda and colleagues might also inform discussions concerning the coercive persuasion of hospitalized patients with eating disorders (Guarda et al., 2007). In their study of 139 patients admitted “voluntarily” to Johns Hopkins University’s eating disorders programs, many felt that they were coerced into treatment. The patients’ average age was 25.2 years, 55% had anorexia nervosa (34% AN-R and 21% AN-BN), 30% bulimia nervosa, and the remainder EDNOS. More perceived coercion was reported among the 35 patients under age 18 than among the 104 adults. Thirty of the adults did not endorse needing admission, but by two weeks into hospitalizations 17 had changed their minds and agreed that they needed hospitalization. No differences were seen between AN-R and AN-BN, although the small sample size may have obscured differences that might be seen in larger samples. Unfortunately, the absence of data in this report on duration of illness, previous treatment, comorbidities, etc., limits what we might infer from this study with respect to SE-AN, a view consistent with other studies (Griffiths et al., 1997).

These studies suggest that with extra time and effort, the short-term weight restoration of patients hospitalized involuntarily for anorexia nervosa might be comparable to that seen in voluntary patients, that a reasonable number of these patients might actually come around to acknowledging their need for treatment, and that some might even be thankful (or at least tell their caregivers that they were thankful) for the fact that they were treated, even against their will. However, the literature contains a paucity of detailed descriptions differentiating those involuntary patients who benefitted in the short and long term from those who rapidly relapsed and even succumbed. The many gaps in knowledge suggest that multisite studies with large numbers of subjects on treatment-refusing SE-AN patients will be required if we’re ever going to be able to make clinical decisions based on evidence rather than, at best, informed whim.

Decision-Making Beyond the Evidence Base

Beyond the few studies reviewed in the previous section, clinicians have little to guide their decisions other than “primum non-nocere,” although exactly how this dictum should be interpreted for justifying the involuntary treatment of patients with SE-AN rapidly becomes quite complicated.

To begin, let us consider the complexities covered over by the terms “involuntary,” “treatment,” and “justified”: all are intricate and always value-laden.
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Involuntary

If by involuntary we refer only to cases where treatment of a patient with SE-AN is mandated by a judge, the number of such cases is much smaller than the number in which patients with anorexia nervosa are, to varying degrees, compassionately coerced into treatment by well-meaning family, friends, or professional caregivers. In contrast, legally mandated involuntary hospitalization is rarely imposed, conducted in very few treatment facilities, and is usually restricted to life-threatening circumstances (Appelbaum & Rumpf, 1998; Carney et al., 2008; Russell, 2001). Although a categorical distinction clearly exists between patients who are legally mandated into treatment and those who are not, in practice “involuntariness” falls along a dimension in which patients differ considerably in the degrees to which they “voluntarily” seek care or sullenly give in under overt or silent protest to all sorts of external pressures pushing them to treatment (Carney, Tait & Touyz, 2007). In all, patients with anorexia nervosa display a broad spectrum of active, passive, and passive-aggressive “voluntariness” and “involuntariness” with regard to attitudes towards treatment.

In assessing a patient’s unwillingness to engage in treatment, and the corresponding potential need for involuntary treatment, we’re obliged to examine the patient’s circumstances, reasoning, and motivations in some detail. Patients’ reasons for refusing to go along with treatment differ considerably. Treatment refusal may be total, selective, or circumstantial. At one extreme, patients may exhibit total denial of illness and refuse to consider any type of treatment. Here, the patient may be frankly deluded, or might have a more fluctuating level of non-belief, or might be impulsively capricious. However, a patient’s treatment refusal might be judicious, resting on a realistic appraisal of the futility of further treatment based on prior experiences, failing numerous competently administered attempts at treatment after numerous good faith efforts on their part and on the part of their caregivers. How do we assess the reasoning and motivations of patients who for years have experienced great psychological suffering, who can’t bear to see the torments to which family members are continuously subjected as a result of chronic, debilitating illnesses, and who see nothing but repeated frustration and futility in any of what’s being offered?

Even if we consider only involuntary treatment by a judge or tribunal, rules and practices for determining whether SE-AN patients merit involuntary status vary considerably from state to state, often within counties and individual jurisdictions within states, and not infrequently from one decision-maker to the next within the same courtroom or tribunal. How different tribunals or judges will decide a given case is often unpredictable. Numerous value-dependent factors enter decisions to approve involuntary status for patients: differences in judicial philosophy, ranging from libertarian to (hopefully, compassionately) paternalistic; differences in judicial temperament, partly reflecting how a judge or
tribunal might be emotionally affected and swayed by a given patient’s or family’s pleas; and differences in personal experiences and pre-judicial attitudes regarding family or friends with severe anorexia nervosa and/or other psychiatric disorders. In the United States, asking a judge to place an SE-AN patient on involuntarily status for treatment in no way assures that the judge will side with family, friends, or professionals who are pressing the case. For example, in invoking involuntary hospitalization for patients with anorexia nervosa, some judges have used the mental health standard that involuntary hospitalization can be imposed if the patient is “gravely disabled,” defined as unable to provide herself with “food, clothing or shelter,” focusing on her inability to provide herself with “food.” Other judges disagree vehemently with such an interpretation. Mental health adjudication by tribunals, for its part, has been shown also to be replete with such “extra-legal” determinants of outcomes (Carney et al., 2011; Peay, 1989; Perkins, 2003). Common law jurisdictions retaining a “best interests” test—a criterion so open-ended that it has been described as an “empty vessel” into which the perceptions or prejudices of the decision-maker may be poured—also encounter disquiet about lack of certainty, as in England and Wales, where its capacity legislation empowers judges of their Court of Protection to make often controversial decisions about whether or not to order involuntary feeding of SE-AN patients (Whiteman, 2012).

Treatment

Treatment options cover the span of activities from outpatient, intensive outpatient, partial hospital, eating disorder hospitalization, residential treatment, and medical stabilization in life-saving situations. Within settings, varieties of individual, family and group approaches, psychotherapies, and psychosocial interventions abound, and varieties of feeding philosophies and medications (and, for medications, different routes of administration) may be considered. In severe cases, questions about nasogastric feedings and supplementations, and in life-saving instances, a variety of other enteral and parenteral feeding methods, electroconvulsive therapy (Ferguson, 1993) and, now, even deep brain stimulation (Lipsman et al., 2013), might be considered. The fact is, unlike Australia, for example, authorization for involuntary treatment in the United States does not give treating professionals carte blanche to do whatever they might want to do, or to treat for however long they might care to continue. In certain locales, involuntary patients may still refuse non-emergency psychotropic medications, or psychotropic medications by injection, or electroconvulsive therapy (ECT) (ECT approval is one of the few commonalities with Australia). In many, if not most, facilities, staff are unwillingly to engage in ongoing battles with patients requiring forced tube feedings. No jurisdiction would undertake deep brain stimulation (DBS) or other forms
of psychosurgery on involuntary patients. Most court-ordered treatments are time-limited, up for review after specified lengths of time.

Even when patients are involuntarily committed to treatment, in the United States many states lack facilities willing (or competent) to accept involuntary SE-AN patients. Furthermore, most of the (few) facilities willing to accept involuntary SE-AN patients are not prepared to accept the legal liabilities involved in accepting such patients across state lines when determinations of involuntary status have not been made by a local judge. Aside from well-supported, structured and encouraging nursing interventions, most facilities are not prepared to administer nasogastric feedings or other coercive treatments to non-compliant patients.

Justified

To justify, of course, means “to make right.” When imposing involuntary treatments for patients with SE-AN, how could—and should—such justification be assessed? Justified to whom? Justified by whom? On utilitarian grounds, if a patient might die without such treatment but can be kept alive through compulsory treatment, shouldn’t that provide prima facie evidence for justification? Tiller et al. recognize that compulsory treatment might be seen as compassionate, not only for saving life, but for relieving patients and their families of the responsibilities of the moment-to-moment agonies of having to decide what steps to take (Tiller, Schmidt & Treasure, 1993). Shouldn’t this speak for itself? Perhaps, at times. But whose “justification” should be satisfied when patients who have suffered for decades with chronic debilitating illnesses and miserable quality of life judiciously determine that they want no more flogging? The patient’s? Are judicious SE-AN patients ever due the same dignity of stopping treatment now afforded to patients with chronic renal disease who desire to stop “heroic measures” entailed by dialysis? Dialysis patients have the right to stop treatment, and simply go off to die. Even the Catholic Church now recognizes that these are not acts of suicide. Or, are the families of SE-AN patients, who can’t abide the idea of their loved ones dying of anorexia nervosa, forever “justified” in demanding that these patients be kept alive and treated at any cost? Or, are professional staff members always “justified” in seeking the right to continue treating such patients indefinitely despite the patient’s strong objections because they can’t abide the idea that they might lose such a patient to starvation?

In a system of true “patient-centered” care, patients are supposed to be able to decide to accept or reject treatment, or to call it quits after a certain amount of time when treatment is shown not to help. Judges or tribunals of libertarian persuasion would lean towards allowing SE-AN patients this determination (except perhaps under the most extreme circumstances). Of course, if the patient’s judgment is determined to be impaired so that they are unable by virtue of a mental illness to make
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personal health judgments—under the extreme circumstances of facing potential death by inanition—the decision might be taken away from them and given to others.

But how unbiased are others’ decisions about what to do under these extreme circumstances? Although the patient’s family, friends, and professional caregivers might choose to see themselves as objective arbiters of what’s right and good for the patient, might they also, at certain levels, be biased by competing interests? Just as some families having to contend with terminal cancer patients are unable to face the fact that little more can be done to save, sustain, or improve the quality of a patient’s life, some families of SE-AN patients simply can’t let go, despite the patient’s wishes. Similarly, some clinicians are unable to give up on their patients; thanks to a range of philosophical, religious, face-saving psychological, and practical considerations, they are dedicated to preserving life at any cost, regardless of low quality of life and poor chances for decent outcomes.

Or, is “society at large” justified in trying to assure that people stay alive at any cost, as happened for years in the case of tube feeding the vegetative patient Terri Schiavo (Blendon, Benson & Herrmann, 2005)? The controversy in England and Wales around divergent Court of Protection (COP) rulings about SE-AN patients illustrates how vexed this question is. COP judges rejected extended force feeding in two instances: one where all treatments had failed over a long period (NHS Foundation Trust v Miss X [2014] EWCOP 35, Cobb J); and in another where a 29-year-old had spent an estimated 90% of the last 16 years being treated in inpatient units as a voluntary or involuntary patient, had some irreversible organ damage, and a BMI so low (7 kg/m²) that the judge accepted that no success had ever been reported (NHS Trust v L [2012] EWHC (COP) 2741, Eleanor King J). However, in the third case of Local Authority v E ([2012] EWHC (COP) 1639) Peter Jackson J, a different judge in the COP, ordered up to 12 months of force feeding for an SE-AN patient with a 14-year history of SE-AN, chronic alcoholism, a BMI of around 12.3–12.6 kg/m² and an estimated 20–30% likelihood of treatment “success,” despite her execution of a “no treatment” advance directive (made while apparently at her high point of competence) and family support for her election for palliative care (which had already lasted for five weeks). Involuntary maintenance of life for such a patient with a clinical history well down towards the chronic and treatment unresponsive end of the spectrum (despite her somewhat better prospects compared to the other two cases) has led some commentators to question compliance with human rights obligations and respect for human dignity (Whiteman, 2012). Finding the sweet spot on the gradient between medical paternalism and respect for patient autonomy is not easy.

If we reject the extremes of keeping individuals alive regardless of their quality of life and regardless of costs, what expected outcomes over what period of time for patients with SE-AN would merit justification
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for involuntary treatment? Before receiving permission to treat a patient involuntarily, to what extent should clinicians be expected to explicitly prognosticate the likely results of their interventions? Should involuntary treatment orders be indefinite (“as long as it takes”) or time limited; if limited, for how long? Which treatment expectations should be acceptable? Medical stabilization: to just keep the patient alive, if only for a few more days or weeks? Keep the patient alive for a little while, as we figure out what to do, and hope that she’ll change her mind and start to feel better about treatment? Restore enough weight to keep the patient going for X number or weeks or months? Or are we justified only if we aim to see that the patient attains full nutritional and psychological health and a decent quality of life? That’s unlikely to happen in SE-AN.

Additional Complexities

These clinical challenges are compounded by a number of additional complexities.

Ethical and Legal Issues

There are deep ethical, clinical, and legal issues at stake here (Carney, et al., 2006). For example, anorexia nervosa questions the assumption of reasonable constancy between the present, past and future “self” that underpins the primacy accorded by the law to autonomous consent as the basis for treatment. Unlike dementia—where rational capacity to understand, retain, weigh, and use information is impaired—anorexic thinking is characterized by misperceptions (of not being underweight) and atypical assessments of risk. This poses serious philosophical challenges (Craigie, 2013).

There are also important cultural differences between (and within) Western and non-Western societies with regard to the weight accorded to values such as individual autonomy, privacy, or paternalism, which have important ramifications for treatment within ethnically diverse communities (Tan et al., 2013). Finally, the very equivocal evidence about whether involuntary treatment yields beneficial outcomes beyond overcoming imminent risks of death for the duration of inpatient care (Guarda, 2008, p. 115; Thiels, 2008) also complicates utilitarian ethical assessments.

Overlaying all of this is the unending variety of clinical types and circumstances. What considerations should be given to the “stage” of illness? The BMI indexed severity scale for anorexia nervosa in the DSM5 represents just one small aspect of staging. Beyond weight, other meaningful factors found to potentially enter staging decisions include motivation, illness duration, obsessionality, bulimia behavior, and various acute issues (Maguire et al., 2012). Further considerations, such as comorbid psychiatric disorders, personality strengths, weaknesses, traits
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and coping styles, substance use, general medical disorders, prior history of treatment attempts, intermittent successes, and subsequent failures, financial constraints, treatment access limitations, family circumstances, the nature and extent of practical and emotional support from family and friends, and the availability and extent of social system safety nets, might also loom large in developing prognostically sophisticated classification systems.

Towards Practical Decision-Making

To this point in our discussion it rather looks like we’re back to “primum non nocere.” In general, clinicians often feel that for younger patients, and for patients who’ve been ill for only a few years, considerable effort should be put into administering treatment, even against a patient’s wishes, and even if involuntary treatment must be imposed, to sustain life and, perhaps, help patients acknowledge that they are in need of help so that they ally themselves with treatment rather than just fight it. The studies described earlier lend some support to that perspective. Few clinicians or even many members of the public would argue with such a position (but see, for example, Draper, 2000; 2003; Giordano, 2003).

Trickier, though, are treatment—and legal—decisions to be made for SE-AN patients who have suffered for decades, who barely sustain life, and who experience the quality of their existences as miserable. The problem is identifying the point at which “enough is enough.”

For any given case the challenge for caregivers is to find just the right therapeutic “sweet spot.” Clinicians and legal bodies should not be dissuaded from intervening by personal cynicism or despair that leads to prematurely signing patients off as hopeless and any treatment as futile. However, clinicians and courts or tribunals should not be swept away with unrealistic therapeutic zeal, where, against all odds, the system keeps flogging patients whose chronic illness has very little likelihood of ever improving significantly (Giordano, 2010; Yager, 2006).

In the latter circumstances, after patients have failed numerous good faith efforts at treatment, and where the patient’s treatment-resistance has ultimately led them to treatment refusal, clinicians have at times invoked the well-established concept of “medical futility.” Arriving at this determination, professional staff, at times with the assistance of local ethics committees, may decide that the most humane clinical approach is to offer the SE-AN patient palliative care including hospice care, essentially comfort care, with no pressure or expectation on the patient to continue eating (Lopez et al., 2010). Under these circumstances, patients may actually relax, ask for some degree of help, possibly improve a bit, continue their existence at a low level for an extended period, or, ultimately, die with more dignity than might otherwise be the case (see Chapter 14, which addresses this challenging issue).
Some Guiding Clinical Principles

If there is one certain fact about implementing involuntary treatment, it is that it should always be undertaken with the utmost dignity and respect. The likely fragile mental state of the patient, especially with regard to self-esteem, needs to be considered. Thiels & Paul (2007) have developed a road map of important clinical principles to be considered prior to the imposition of involuntary treatment. The following should be taken into account:

1. Coercion should in no way preclude psychotherapy, nor should it be a contraindication for it.
2. Where the law permits, and as there is a need for ongoing care, any application for guardianship should be for between three and six months.
3. The cut off for involuntary admission should be a BMI of less than 13 kg/m2, as there appears to be some evidence that the risk of dying increases below this cut-off. However, this should not be regarded as the sole parameter and other indicators such as suicidality, electrolyte imbalance, and cardiac arrhythmia should also be considered.
4. It is a given that a successful outcome will be the preservation of a workable therapeutic relationship and the preservation of a supportive milieu. In this context it is therefore essential that coercion be the least restrictive possible and for the shortest duration of time.
5. From the outset, every effort should be made to encourage the patient to eat independently.
6. The focus of therapeutic intervention should not solely revolve around independent eating and weight gain.
7. The involvement of family members is crucial and should occur whenever the opportunity presents itself.
8. The ultimate aim is not a target weight but the return of a collaborative relationship without the need for coercive powers.

Whenever there is a breakdown in the collaboration between clinician and patient, and coercive treatment such as nasogastric feeding is enforced, there is a real risk of inflicting psychological distress as evidenced in the following vignette.

I didn’t know what it was going to involve. I hated pain . . . I was afraid, so scared. The tube looked so hard and long. I began to cry . . . the hideous piece of plastic tubing was being forced down my left nostril . . . I was screaming . . . My head thrashed wildly on the bed whilst my body squirmed or moved like a wounded fish out of water. I cried . . . Nothing can or will ever remove the memory of that tube. However, this tube was going to save my life . . . But I decided that I
didn’t want this tube inside of me . . . not the fluid flowing into me through the tube. The most sensible thing in my eyes to do was to pull it out. But I didn’t want any pain.

I gently pulled the tube protruding from my nose and it was sore. I was so afraid and scared of what I could do to myself and also scared what the staff would do to me . . . I lifted my feeble arms and fingers. I placed the tube between my thumb and forefinger and gently yanked it. Something moved inside me. I could now feel the tube inside my stomach. My mind ran amuck. I was so confused. Out came the tube, one hell of a long tube. I hadn’t realised how long it actually was (I later found out that it was 3 feet long).

Touyz & Beumont, 1992, p. 68

This graphically illustrates why so much care and consideration is needed before advocating enforced nasogastric feeding, which should only be implemented in those rare occasions in which the patient is in imminent danger or unable to respond to more conservative methods (Touyz, 1998, Carney et al., 2006). There will be occasions where the patient is insightful as to their inability to eat and may even request or readily accept nasogastric feeding. Under such circumstances with the full collaboration of the patient, such interventions usually result in minimal distress. However, the risk here is that when it is determined that the nasogastric tube is not clinically indicated, the patient may argue they are unable to receive adequate nutrition without it and stop eating every time an attempt is made to remove it.

Conclusion: A Way Forward?

Cases of SE-AN pose many complexities, at many levels: in conceptualizing the decisional capacity aspects of the illness (Beumont & Carney, 2003; 2004; Beumont & Touyz, 2003), in framing of bioethical questions about decisional autonomy (Giordano, 2005; Kendall, 2014), and in determining whether coercion has any role (Andersen, 2007; Rathner, 1998).

As previously indicated, in the specific case of arrangements about the use of involuntary treatment of SE-AN cases within federal systems of law, uniformity of legal architecture cannot be expected. This is because specific legislative authority to use force will usually be needed, given that any common law inherent powers tend to be narrow or uncertain, and because such statutory provisions will be embedded in wider mental health (or child protection) laws which fall under the constitutional powers assigned to the constituent units of the federation rather than being reposed in the central government (Halberstam & Reimann, 2014). Consequently, there is considerable variance in the international pattern of laws regarding mental health generally (Gray et al., 2010) and anorexia in particular (Carney et al., 2006), as well as some uncertainty about the boundaries of what is
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permissible with regard to involuntary anorexia management in particular countries (Maher & Nwachukwu, 2012). Civil commitment seems rarely used (or much discussed) in the USA (Testa & West, 2010, p. 37).

Irritating as it is for clinicians working within a federal system of law, it is not sensible to anticipate that greater uniformity within a federal system is easily realized. Although the Australian federation has been described as “one of the most centralized federations in the world” (Saunders & Foster, 2014, p. 102), Canada’s small population, the “bijural nature” of civil law in francophone Quebec, along with provincial control of private law, are among the “numerous forces that hinder unification” (Grenon, 2014, p. 190). Likewise, US commentators have concluded that there are “significant non-uniformities between state and federal laws and among laws of states” (Maxeiner, 2014, p. 520). To compound the difficulties, areas of private law such as health are characterized by the availability of a smaller toolkit to promote uniformity of approach (such as no central government powers), leaving more weight to be carried by measures such as inter-governmental coordination or civil society agency lobbying (Halberstam & Reimann, 2014, pp. 31–32).

Notwithstanding the legal complexities previously described, and when treating patients with SE-AN, the clinician will inevitably encounter a situation in which they need to stand firm in the face of an ever increasing avalanche of desperate pleas and at times even open hostility. This scenario is often enacted when admission to hospital becomes inevitable and can escalate rapidly into a full-blown emotionally charged crisis. It is also not unusual in such circumstances for family members to take diametrically opposed views as to what needs to transpire. This adds further grist to the mill. It is at times like this, against a backdrop of life-threatening medical complications, that the patient declares that they should have the right to determine their own fate even if this should lead to their untimely death (Touyz, Polivy & Hay, 2008). It is difficult to conjure up many other instances in medicine where the clinical imperative to treat runs into a steadfast refusal to consent at the very time when the available capacity of all is stretched to almost breaking point. At times like this when medicine and the law collide, clear clinical guidelines based upon evidence are needed to make informed decisions. This is clearly preferable to the outcome of disagreement between clinician and patient being decided within a courtroom setting where barristers and lawyers rule supreme and the course of treatment is ultimately decreed by a judge or magistrate (Carney et al., 2006). Fortunately, there are now, for the first time, clinical practice guidelines for treating patients with SE-AN (Hay et al., 2014, see also Chapter 6 by Touyz and Strober). However, notwithstanding this, there remains the urgent need to address the issue of mental capacity in such patients. There is a need to connect neuropsychological concepts pertaining to decision-making to that of mental capacity with the added caveat of including emotional processing (Elzakkers et al., 2014).
an understanding may lead to a better conceptualization of the more “fundamental psychological mechanisms” that underlie mental capacity, which would enable the development of more tailored assessment tools to assess mental capacity in those patients where their illness has taken a more chronic course.

In conclusion, the question needs to be asked as to whether the law has a role to play in the management of patients with SE-AN. It is perhaps still too early in the piece to provide a definitive answer, but the need for more research on this topic is compelling (Touyz & Carney, 2010). What we can say is that it does appear to be of benefit “in overseeing proposed forcible detention and treatment and providing for overriding consent, and can play a more general role in setting up frameworks for protecting rights” (Carney et al., 2006, p. 162). Ultimately, treatment needs to be a collaborative exercise “to ensure greater protection for personal directives.” The therapeutic milieu should always encourage such patients to become more effectively involved in their own treatment, be enabled to make informed choices and in the least restrictive environment (Touyz & Carney, 2010). We have argued cogently that if such important treatment guidelines can be endorsed and subsequently implemented, then there is a good chance that the need for coercive treatment may diminish. Until such time, “the goal of providing the opportunity . . . should be placed beyond individual autonomy.” Thiels (2008) has summarized this point well by concluding that the enforced hospitalization of a patient with SE-AN is not only necessary but ethically responsible and should be addressed by legislation. Only once the patient has been admitted to a specialized eating disorders facility can the journey towards recovery begin. With the necessary training and skills, nurses should be able to encourage the patient to eat without having to resort to forced or nasogastric feeding.

References


Is Involuntary Treatment Justified in Patients with SE-AN?


Managing Severe and Enduring Anorexia Nervosa


Severe and Enduring Anorexia Nervosa

A New Approach to its Diagnosis, Features, and Treatment

J. Hubert Lacey and Richard Sly

When Gull (1874) and Lasègue (1873) first described anorexia nervosa there was an expressed optimism about the potential for recovery from the illness. Throughout the following century, this optimism was supported by a series of clinical descriptions by charismatic clinicians who indicated treatment for anorexia nervosa was largely successful, with few accounts of poor treatment outcome. However, more recently, robustly designed prognostic studies uncovered data that spoke of a different truth: that the future for those receiving treatment for anorexia nervosa was often bleak. For example, Von Holle et al. (2008), using conservative criteria of recovery, reported that after ten years of illness, a tenth of people with anorexia and bulimia nervosa had recovered, and only 16% with index anorexia nervosa and 25% with index bulimia nervosa meeting recovery criteria after 15 years. This view supported a prior meta-analysis in which Steinhausen (2002) identified 119 studies of 5590 participants with length of follow-up of 1–29 years. Of these participants, a mean of 47% recovered (range 0–92%), 34% improved (range 0–75%), and 5% died, while 21% developed a chronic or severe and enduring eating disorder (range 0–79%). Even these figures give a gloss to reality, and the clinical reality is likely to be starker than the research figures indicate (Von Holle et al., 2008).

“Chronicity”

What constitutes “chronicity” in anorexia nervosa lacks definition (Tierney & Fox, 2009) and what definitions have been attempted are largely arbitrary. Some, such as Steinhausen, argue chronicity should be assessed based on the duration of illness alone, and that after seven years of illness the likelihood of recovery is low, although not impossible. The “passage of time” debate in assessing chronicity is based on little strong evidence, and as a result there is no agreement on how many years of illness warrants the label (Touyz et al., 2013). It is argued that psychological presentation, rather than time, should be taken into account when defining chronicity. However, as elsewhere in this debate, there is little evidence that marked
abnormalities on standardized measures is indicative of prognosis. Instead of such measures, then, some argue that meaningful diagnosis can only be made using clinical interview. Again, the evidence behind this assertion is lacking. “Chronicity” also has an inherent issue of nomenclature, in which the very term carries an implication of there being little chance of recovery. Many clinicians feel, and have indeed demonstrated, that recovery is never wholly out of reach (Strober, 2009; Steinhausen, 2002). As a result, the concept of “chronic AN” as a diagnostic term has been recently replaced with an inherently more inclusive and hopeful term: severe and enduring anorexia nervosa (SE-AN).

Severe and Enduring Anorexia Nervosa (SE-AN)

The diagnosis of SE-AN requires six core characteristics to be present, three are shared with acute anorexia and three are specific to SE-AN. The thinking of people with anorexia nervosa, whether acute or long-term, is archetypal and diagnostic. Indeed it is pathognomonic. The psychopathology of SE-AN is dominated by a pursuit of thinness combined with hatred of the body. The key element—and one that is unique to this condition—is an irrational phobia of “normal” body weight. People with anorexia nervosa do not have a mere dislike or aversion to putting on weight; it is an intense, overwhelming fear. Furthermore, it is not obesity of which they are fearful, but normal body weight. There is a pursuit of thinness, a hatred and fear of a normal weight, and a profound disparagement of a womanly shape.

These beliefs lead to behavioral changes with a view to achieving weight loss. The behavior, such as dietary restriction, laxative abuse, vomiting, or excessive exercise, leads to weight loss, and body weight falls below BMI 17.5. This weight loss in turn leads to an endocrine disturbance, sufficient, if a woman, to stop menstruation, and in both sexes leads to low sexual drive. It’s important for clinicians to remember that it is a phobia that leads to weight loss behavior, and not vice versa.

The illness must have been persistent and periods of remission are not common, though do not exclude the diagnosis. Although there can be no absolutes in clinical medicine, the data referred to suggests the diagnosis of SE-AN should not be used unless the illness has been consistently present for a period of seven years at least. If the patient has had a number of remissions the length of illness should be correspondingly increased and most experts wouldn’t feel comfortable making the diagnosis in a patient with a fluctuating course unless there had been eleven or more years of ill-health.

SE-AN sufferers are highly resistant to treatment, demonstrating consistent disengagement from treatment and with numerous episodes of premature termination of treatment. Further, to meet this criterion, patients should have failed to respond to a broad spectrum of therapies
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specifically designed to address the eating disorder and delivered by different therapists. For example, someone who has had years of psychodynamic therapy alone, without achieving weight recovery, cannot be said to have been adequately treated and should not be regarded as having SE-AN. The same can be said of those who have solely had cognitive behavioral therapy (CBT), even if the type of CBT has varied or has just consisted of systemic therapy or nutritional counseling. No one knows the treatment that will get a particular patient better, so chronicity cannot be assumed until a reasonable range of treatments, which because of its database must include CBT, has been tried. Further, a patient who after many years is offered a completely different model of treatment is likely to be more motivated. All these patients with different treatment histories will share many features of the effects of long-term starvation, and the behavior they use to maintain their starvation will also appear similar in the clinic but the patients resistance to treatment, or their motivation and prognosis, are likely to be very different.

Severity is best assessed not by questionnaire but by the effect of the illness on the patients’ quality of life and health. Sufferers are often socially isolated, unemployed, or have not fulfilled their potential, which is often great. In our own study the level of education was high: 75% had a college degree but only around 40% were employed. The patients tend to be intensive users of GP and health services and are often dependent on welfare. Comorbidities such as depression, obsessional features, and addictive and self-damaging behavior are commonly demonstrated.

These six diagnostic concepts outlined will guide the clinician through the obvious pitfalls and traps. SE-AN should not be used as a diagnosis when a patient has a lengthy history of being symptom-free, is a patient who is recovering despite their illness duration, or is a patient who has been inadequately treated and not offered a broad array of treatment modalities.

Psychological Features of SE-AN

SE-AN patients are often perfectionistic, demanding impossibly high standards from themselves and those around them. They are typically inflexible and rigid in their thinking, and demonstrate an at-times overwhelmingly strong sense of self-determination. In consultation, it is often easy to sense the patient’s vulnerability; they have cut themselves out of reality. Their level of emaciation is strongly denied, even if asked to calculate their own BMI; the understanding of their body and the concrete, clear worlds of biology and physics become parallel tracts. Even a well-educated and otherwise lucid patient will claim their metabolism is different to everyone else’s and that their intake of food or levels of over-exercising behavior are unrelated to weight, seemingly a denial of the laws of thermo-dynamics. This is very definitely not a question of psychosis. These skewed judgments are formulated from a strongly overvalued idea.
On occasion, this unreality can be breached by the clinician relating the patients’ assertions to Newton’s Laws or common knowledge of metabolism. The patient hastily patches up this breach; the cognitive dissonance that such a conversation uncovers can be enough for them to not attend the next appointment, or to disengage in general. Fully established SE-AN does not allow for any sense of cognitive dissonance to be allowed to linger for too long. The patient will rationalize that they do not need help and can deal with their own difficulties in their own way and in their own time.

It is sometimes said that SE-AN patients are mistrustful of interpersonal relationships. In reality this is fear of the aforementioned cognitive dissonance that conversations with skilled clinicians may evoke, and from the pressure to gain weight that accompanies clinical relationships. As a result, they just wish to avoid their doctor. The terror of weight gain generates almost paralyzing levels of anxiety: any food intake is perceived as loss of control. Cognitively trained therapists will see this as distorted thinking and dynamically trained therapists will view this as ineffectiveness due to an earlier trauma. Practically, the distinction is irrelevant, for either way there is an adverse impact on conceptual, perceptual, and decision-making abilities.

SE-AN patients are distressed by their mood. They will describe being depressed but the clinician should avoid the temptation to “fix” this with anti-depressant medication. The mood change is usually understandable when considering the specific context of the patient’s lifestyle and problems. Depression and anxiety are exacerbated by the physiological and metabolic disturbances that accompany starvation and malnutrition, although conversely, for a while they are made worse with weight gain, which can be seen as being part of the survival mechanism of anorexia nervosa itself. Patients find it comparatively simple to talk about sadness and anxiety, but in reality, the dominant emotion in SE-AN, in our clinical opinion, is anger. This in itself is not an easy thing to talk about to a GP, or newly acquainted clinician and is often missed, however, it is probably the most crippling and dominant emotion of the condition. The full extent often only becomes declared during treatment.

It should not be forgotten that SE-AN patients have more than enough emotional intelligence to sense if their clinicians have given up hope on them. They will be adversely affected by a less than optimistic view regarding the long-term outcome of the disorder; they will use this lack of belief of them to prove their clinician right, and give up on recovery themselves.

**Social Features of SE-AN**

SE-AN patients retreat from the outside world, and into their own: an anorexia-generated world. Concentration is typically impaired as thoughts become increasingly limited to food and weight. Friends and
family are marginalized as a result of this inner-world taking precedence. They report feeling “left behind,” as they see their peers make their way through the milestones of adult life, the milestones they themselves have assuaged in favor of preserving their “anorectic bubble.” The boundaries of their world narrow. These patients pose a significant burden to parents, carers, and the community as well as their professional carers (Striegel-Moore et al., 2008; Strober, 2004a). The denial of illness that is typical in these patients leads them to avoid doctors and therapists. Frequently, families and carers get caught up in this. The “anorectic” part of the patient splits carer from clinician.

**Physical Complications of SE-AN**

The physical complications of acute anorexia are, by nature, progressive. The persistent acute emaciation in SE-AN patients strongly contributes to significant physical co-morbidity that necessitates repeated presentations to general and specialist medical facilities (Arkell & Robinson, 2008; Birmingham & Treasure, 2010; Robinson, 2009; Treasure et al., 2001).

Bones become demineralized of calcium and are liable to fracture, and osteoporosis and osteopenia become particular problems for patients with SE-AN. Chronic exercise can lead to early stress or frank fractures after only slight over-activity, yet patients will often continue to run even when they know they have a fracture and are in pain. The psychological pain of loss of control due to exercise cessation is more powerful that the physical pain of activity on badly damaged legs.

People with SE-AN at low weight describe being intermittently dizzy: a combination of electrolyte abnormalities and intermittent phobic anxiety. Tachycardia and low blood pressure is the norm if and when an SE-AN patient undergoes nasogastric refeeding, whether under restraint or not. The panic brought on by their weight phobia preconditions the body to sympathetic discharge. Chronic hepatic and cardiac complications do occur but are rare. SE-AN patients are sensitive to cold and interestingly wake early in the morning, like patients with biological depression, which is similar to patients with acute anorexia. The authors have wondered whether these phenomena follow starvation and emaciation and have evolutional survival value; put simply, it is the early bird that catches the worm.

Physical changes, such as dry skin and weak muscles, follow emaciation. SE-AN patients who vomit typically experience a swelling in their salivary glands, show Russell’s sign, and their teeth can become significantly eroded, particularly on the palatal surfaces. The difference from acute AN is that these features are persistent in those with SE-AN: the salivary glands remain permanently swollen, the knuckles ulcerate, and teeth need to be extracted.

Low weight causes infertility in the majority of women with SE-AN. Most have major concerns about their potential to have children, and can be reassured that even though they may have had decades of amenorrhea, their
fertility upon weight restoration is unaffected. It should also be noted that even at persistent low weight, one cannot assume that ovulation will not take place. Occasionally it does, and SE-AN patients should be counseled that they might be fertile and be aware of the need for contraception.

Almost every body system can be adversely affected by progressive starvation (Mehler, Krantz & Sachs, 2015) and some of the complications are permanent. Long-standing AN has the highest mortality rate of any mental illness, with 20% dying due to suicide, emaciation, or inter-current disease (Steinhausen et al., 2000).

**Multi-Impulsive Behavior**

There is an association between SE-AN and addictive or self-damaging behavior, also known as multi-impulsive behavior. This includes abusing alcohol, drugs and other substances, unwise sexual activity, and overspending or instances of shoplifting. This behavior is experienced as being “out of control.” Their function is to replace and quash uncomfortable feelings that trigger this behavior (Lacey & Evans, 1986). In addition to feeling out of control, multi-impulsive behavior is associated with low levels of self-esteem, depression, and that most dominant of emotions: anger. Although one impulsive behavior dominates, any potential others are recessive, until needed again. For example, a patient may abuse drugs or alcohol for a spell, during which time the eating disorder becomes quiescent.

Anorexia nervosa, addictive and self-damaging behavior are all highly visible symptoms of unseen underlying problems that serve to protect the individual from real difficulties that they cannot handle. Giving up this pernicious form of anorexia nervosa is particularly difficult, for in so doing, the individuals’ coping mechanisms are abruptly stripped from them.

**Alcohol and Drug Abuse**

As previously mentioned, anorexia nervosa and substance abuse disorders can and do exist side-by-side, although at this stage the mechanism is not understood (Lacey, 1993; Hudson et al., 2007). Some believe that both disorders are manifestations of a common shared underlying cause or set of causes; others that the two disorders may share the same risk factors. Indeed, it is theorized that eating disorders and substance abuse disorders are manifestations of a predisposition towards being impulsive. This is thought to relate to the opioid compounds that occur naturally in the body and act like opiates in specific circumstances.

The relationship works in both directions, that is, just as alcohol and substance abuse may occur in anorexia, so eating disorders are common in women with alcoholism. Figures as high as 30% have been quoted. Of these, one-third was diagnosed with anorexia nervosa and two-thirds with bulimia nervosa. The eating disorder is usually primary, preceding the alcohol abuse (Beary, Lacey & Merry, 1996; Lacey & Mourelli, 1986).
Deliberate Self-Harm

Acts of deliberate self-harm (DSH), including cutting, scratching, burning, and, interestingly, swallowing of objects such as batteries or pins, occur in about 50% of SE-AN patients (Lacey, 1993; Kent et al., 1997; Morgan & Lacey, 1999). The most common form of DSH tends to be cutting, and is most often done on the arms, legs, or abdomen with a pin, knife, or razor blade. The area of the body that is cut usually has no significance other than ease of access. Individuals may pick at light cuts or scratches so they don’t heal easily. When cuts are so severe that they require stitches, the patient may subsequently remove these upon returning home, as a continued manifestation of DSH.

In women, the most pernicious forms of self-damage are cuts and stabbings to the vagina, usually internally, and breasts. Light cuts in the labia minora in the vulva are sometimes used as a means of faking menstruation, but more usually it’s an indication of profound psychological illness. It should be noted that this behavior is much rarer than cuts elsewhere on the body. The authors have noted that the patient usually presents with a history of borderline disorder and a history of sexual abuse is not infrequent. Cuts to the breasts are similarly a feature of significant disturbance. Cuts are made to the Tail of Spence, the conical shaped area on the lateral side of the breasts that runs into the axilla.

Patients who engage in DSH may burn themselves with a lit cigarette, or if no implements are at hand, they may bang their heads or fists against a wall, causing cuts and bruises that are explained away in credible tales.

Young adolescents may display their wounds, almost a visible badge of emotional stress aimed at those around them. Surprisingly, for most and certainly for those with long-term illness DSH is not a cry for attention. They invariably try to cover their scars or burns with long sleeves and trousers. Some patients feel numb or “dead inside” and report that cutting (or scratching or burning) facilitates the need to feel something, even if that something is physical pain. Other patients with DSH are aware of a build-up of tension so great that an equally intense release is needed. Following carrying out the cut, scratch, or burn, they experience a rush of endorphins, which effectively releases all tension and stress, temporarily at least.

Overdosing

Most overdoses are impulsive and not planned (Kent et al., 1997). SE-AN patients are not usually actively suicidal, though death may occur by omission. An overdose is more typically a means of indicating feelings of desperation or depression. More often than not, compounds containing aspirin or paracetamol are used, which in an emaciated patient are particularly dangerous, leading to liver and kidney damage and death.
Sexual Behavior

Due to SE-AN patients’ weight typically falling below the threshold necessary for sex hormone activity, both men and women with SE-AN report a lack of libido or sexual drive (Morgan, Lacey & Reid, 1999). Some SE-AN patients who purge, however, are at a higher weight and so are sexually aware, though they lack the maturity to handle it when in their anorectic bubble. A multi-impulsive SE-AN patient disparages their body, hating and despising it and, often under the influence of alcohol, becomes sexually disinhibited. This is not promiscuity. It stems from low self-esteem and the inability to value either self or body. The sexual activity is described as punitive and pleasureless (F. Rafael, personal communication, 2005). Sometimes, pedophiles, or men who are inadequate emotionally, are drawn to the immature body of a woman with chronic anorexia nervosa. Others describe being drawn to the SE-AN’s boyish figure. Such men may be particularly interested because the girl or woman is of a legal age to consent and hence they avoid prosecution.

At a low weight, pregnancy is possible: an occasional ovulation may occur. The patient has no indication she’s fertile so should always be cautioned to use a contraceptive.

Prognosis

As noted at the beginning of this chapter, the prognosis of eating disorders in adults is poor. Publications from the last three decades have indicated a deteriorating response. By the beginning of this century, only 25% of bulimics and 16% of people with anorexia nervosa were making a full recovery when measured on strict criteria (Von Holle et al., 2008). Some believe the deteriorating response is because of pathoplasticity: the tendency for these disorders to become associated with multi-impulsive behavior and the more complicated treatment programs that are needed as a result (Lacey & Evans, 1986). Others suggest that adolescents with anorexia nervosa are not treated with sufficient vigor. Significant numbers of children with eating disorders are being missed, misdiagnosed, treated too late, or too weakly (BBC, 2013). The current trend is to restrict the use of inpatient treatment to a brief admission with only partial weight recovery before discharge to outpatients. The policy is financially driven but rationalized by emphasizing the advantage of keeping the adolescent in the home and school environment. The result is that patients spend many years at a low but medically safe weight during which time the psychopathology becomes entrenched and chronic until it becomes unreachable by therapy. Recently, Madden et al. (2014) have shown how this brief inpatient treatment might work, albeit with intensive follow-up care. Generally, there is a paucity of knowledge (Madden, Hay & Touyz, 2015) and much disquiet amongst clinicians.
Some wonder whether CBT, which is experimentally designed to treat eating disorders, is not being followed exactly as the manuals describe. Others, on the contrary, believe that pure CBT is too narrow and a more eclectic therapy should be used, where cognitive and behavior methods are mixed with dynamic insight-directed therapy or family therapy. The evidence is not in place at this stage, but the strong message must be that anorexia nervosa has to be treated vigorously early in adolescence or it is likely to become severe and enduring.

Treatment

We do not know—yet—the best course of action for treating patients with anorexia nervosa. There have been only ten randomized controlled trials (RCTs) and these have involved fewer than 400 patients. These studies have been criticized for having high dropout rates, approximately 30%, and non-conclusive results. Sadly, there is no clear treatment of choice despite the seriousness of anorexia nervosa. There has been only one RCT for SE-AN (Touyz et al., 2013). Further, there is no evidence that any one model of psychotherapy is superior to others. Although current clinical opinion regards CBT as the “best hope” for eating disorders, when applied to anorexia nervosa, results have been inconsistent and, indeed disappointing. As a result, in clinical practice there is a tendency to ring the therapy changes in a way that isn’t scientific. Wonderlich et al. (2012, p. 467) write “Clinicians often modify treatment, target co-morbid complicating disorders, switch to intermittent supportive treatments, or intensify treatments with higher levels of care, all of which are based on clinical decision making with a minimal of scientific guidance.”

Expert opinion, rather than clear evidence, is the hallmark of the recommended treatment of adults with anorexia nervosa. Because of the lack of clinical evidence, the general response is to recommend the least restrictive treatment compatible with safety. Most national guidelines (NICE, 2004; APA, 2000; Beumont, Hay & Beumont, 2003; Hay et al., 2014) agree that there should be a continuum of care, with outpatient individual therapy being favored if a patient is medically stable. There is no “best” outpatient therapy and significant dropout is often reported in published treatments and is even more common than reported in inpatient populations (Halmi et al., 2005; Dare et al., 2001; Bulik et al., 2007). CBT has been shown to be effective in relapse prevention in two independent trials for adults, including many individuals with SE-AN (Pike et al., 2003; Carter, Woodside & Kaplan, 2000).

With the absence of clear scientific guidelines, clinicians who treat patients with SE-AN resort to modifying existing treatment protocols. They seek out alternative strategies that make accommodations for patients’ chronic status, paying close attention to comorbidities and blending supportive, harm-reduction and recovery-based strategies.
Wonderlich et al. (2012) state that in the attempt to meet this therapeutic challenge, “treatments may devolve into relatively unfocused, intermittent, supportive interventions, where goals become unclear and monitoring of clinical status becomes impressionistic and imprecise” (p. 476).

Treatment resistance has traditionally been defined as a lack of improvement in eating disorder pathology following intervention. Longer duration of illness is a predictor of treatment resistance and mortality in the eating disorders (Reas et al., 2000; Keel et al., 2003). Anorexia nervosa patients typically develop a history of negative treatment experience and repeated treatment failures and disengagement (Woodside, 2004). In this situation it is common for patients and clinicians alike to experience a sense of hopelessness about the possibility of change (George et al., 2004).

Touyz and his collaborators, which include the first author (Touyz et al., 2013), discuss the challenges in tailoring treatment for individuals with SE-AN. As weight phobia is pathognomonic to the disorder, any treatment that prioritizes weight gain above all else will lead to avoidance of treatment or premature termination of treatment at the first opportunity. Globally, to date, treatment programs are limited in their capacity to treat these patients and it is not uncommon for non-specific medical palliation to become the default care (Lopez, Yager & Feinstein, 2010; Strober, 2009).

Given the choice of palliation, especially for relatively young individuals with SE-AN, and taking the challenges and complexities of treatment into account, a different approach is needed, and evidence for its efficacy is crucial (Robinson, 2009; Goldner, 1989; Yager, 1992; Vitousek, Watson & Wilson, 1998; Williams, Dobney & Geller, 2010; Strober, 2004b). Such a paradigm must reflect the severe and enduring nature of this debilitating disorder, the weight phobia at its core, and the understandable avoidance of weight restoration at all costs. Rather than recovery being the basic premise, treatment should focus more upon retention, engagement, and improved quality of life with harm minimization (Strober, 2009; Williams et al., 2010). Such an approach needs to bear in mind the challenges of treating patients with long-standing low levels of motivation for change, neurocognitive deficits, and a self-view and lifestyle dominated by the illness (Strober, 2004; Schmitt & Treasure, 2006; Treasure & Russell, 2011; Hatch et al., 2010).

Any treatment for SE-AN must engage patients by offering something more than weight gain. SE-AN patients wish to address their quality of life and mood perhaps more than anything else. The new treatment would need to engage the patient by being clinically and personally meaningful. Two approaches, in need of adaptation for the SE-AN client, have promise. A modified cognitive behavioral therapy for anorexia nervosa (CBT-AN) (Pike et al., 2003) has demonstrated efficacy for relapse prevention for adult anorexia nervosa, and a modified specialist supportive clinical management (SSCM), (McIntosh, Jordan & Bulik, 2010; McIntosh et al., 2006), a treatment that has shown promise in adult anorexia nervosa.
Although individuals with SE-AN participated in the initial studies evaluating both CBT-AN and SSCM for adult anorexia nervosa, neither of these studies focused exclusively on SE-AN until the Touyz study.

**Specialist Supportive Clinical Management (SSCM)**

SSCM mimics usual outpatient clinical practice by combining features of clinical management and supportive psychotherapy. It is flexible, tailored to the individual patient and to their specific needs and goals. Clinical management includes education, advice, care and support, and fostering a therapeutic alliance that promotes adherence to treatment. Supportive psychotherapy aims to assist the patient through use of praise, reassurance, and advice without mandating change. There is also collaborative goal setting and symptom monitoring. Active strategies are suggested but not enforced. The abnormal dietary patterns typical of anorexia nervosa are addressed in SSCM through education about normal eating and increase in weight, strategies for weight maintenance, information about energy requirements, and re-learning to eat normally. Information is provided through discussions and in handouts. Manualized SSCM for SE-AN was modified such that weight gain was not prioritized. Instead, SSCM encouraged patients to make changes to improve quality of life. The rationale for this emphasis in treatment (Touyz et al., 2013) is that research suggests that treatments targeting psychosocial functioning are especially appropriate when there has been repeated relapse or a long duration of illness. By helping individuals improve quality of life, they will be motivated to make progress on their core eating disorder symptoms.

**Cognitive Behavioral Therapy (CBT-AN)**

CBT-AN follows four clearly defined phases of treatment, each of which is manualized and adapted for SE-AN. Unlike SSCM, CBT-AN is an active treatment aimed at restoring normal eating habits by challenging underlying beliefs and through cognitive restructuring and change in behavior. It involves planned “homework” and it sets clear aims.

The CBT-AN for SE-AN is based on the CBT-AN protocol developed by Pike et al. (2003), which focuses on the cognitive and behavioral disturbances linked to the core features of anorexia nervosa and also more global issues associated with anorexia nervosa, including motivational and schema-based work. Phase I provides specific strategies for initiating treatment, orienting patients to CBT and addressing issues of motivation. Phase II focuses on strategies for addressing weight gain, cognitive distortions, and behavioral disturbances associated with eating and weight. Phase III expands the focus of treatment to schema-based work, which addresses relevant issues extending beyond the specific domains of eating and weight. Phase IV focuses on reviewing the course of therapy,
consolidating gains, and preparing continuation work for after therapy ends. Although the four phases of treatment are described sequentially, the treatment is flexible in terms of applying modules of the protocol as needed throughout the course of treatment. CBT-AN for SE-AN is modified in the way SSCM is modified, to reflect the shift in treatment goals; weight gain and recovery from core features of the eating disorder were not assumed to be treatment priorities. Instead, treatment goals were set collaboratively and weight gain, though encouraged, was not mandatory.

These two treatments were used (Touyz et al., 2013) with a severely-ill SE-AN population with significant emotional, social, and medical problems. The sample had a mean age of 34 years and had been ill for an average of 17 years. Most of the sample was unemployed, despite having had higher education. Most had never had an emotional relationship let alone a meaningful one. The majority were having medical treatment and three-quarters were causing medical concern.

The study yielded a number of surprises that have changed the way we view the treatment of SE-AN. Unlike any other anorexia nervosa treatment study, only a small minority (12%) of patients prematurely terminated from treatment. Furthermore, the completion rates were the same, regardless of treatment. The most likely explanation of this frankly staggering completion rate is that weight restoration was not central to treatment, and therapists worked on areas that the patient herself deemed important, in particular, quality of life and social engagement.

The comparative efficacy of CBT and SSCM was comparable. No panacea was found. Treatment response was similar irrespective of orientation. Both treatment groups reported significant improvement in quality of life measures, mood disorder symptoms, and social adjustment. Those who received CBT showed a greater improvement in eating disordered symptoms and a greater readiness to change their illness, while those who had SSCM, had greater improvement in health-related quality of life with improved mood and social adjustment. This may provide clinicians with an indication of which patients should try which of the two approaches first.

Although weight gain was not emphasized in either treatment, no patient lost weight and almost all had gained weight by the end. Four patients, since the end of the study, have become mothers, a testament to how their insular anorectic bubble has been burst. This confirms the authors’ belief that improvement in areas outside the core pathology can significantly improve their quality of life, causing a domino effect on patient well-being and disease burden, which will in turn further motivate and enable them to make progress on their core ED symptoms.

These findings challenge the view that individuals with an enduring course of anorexia nervosa have little or no motivation to change, are unlikely to respond to conventional psychosocial treatments, and have a high treatment dropout.
SE-AN patients were shown to be retained in treatment and demonstrated significant and meaningful improvements with therapy. The authors argue that the findings have public health implications, in particular that specialist clinics should work with people with SE-AN and not pass them to family practitioners or generic services nor give up on them in any other way. These findings strongly suggest that there was perhaps not so much “wrong” with the SE-AN patients of the past, but there was something wrong about the SE-AN treatments that were used to treat them. Now, at last, there are the evidential foundations upon which to build.

Coerced Treatment of SE-AN

Patients with a diagnosis of SE-AN are likely to have experienced various forms of coercion from health professionals during the course of their illness. This ranges from strong persuasion by clinicians to engage with and remain in treatment, to formally compelled treatment under a legal restriction (Elzakkers et al., 2014).

Those with SE-AN have, by definition, received treatment on numerous occasions across different treatment modalities. They are likely to have at some point(s) experienced levels of perceived coercion stemming from clinical or familial persuasion that verges on de facto compelled treatment. In treatment for anorexia nervosa, it is common for “strong persuasion, brow beating, or even outright moral blackmail” to be deployed (Carney, Tait & Touyz, 2007, p. 390). Clinicians use this form of leverage to try to obtain treatment compliance, with patients being directly or indirectly notified that a lack of adherence to treatment would likely result in the enforcement of legally compelled treatment. This is common, although, it should be noted, is not encouraged as best practice by any of the clinical governing bodies. These experiences magnify the power imbalance between patient and clinician, and can delay or stop dead the development of therapeutic alliance. It is also likely to impact upon future engagement with treatment, and opinions of clinicians in general. Guarda et al. (2007) studied perceived coercion in 139 patients with eating disorders at admission and again two weeks into inpatient treatment. Those with a diagnosis of anorexia nervosa reported higher levels of perceived coercion and pressure and a lower sense of procedural justice compared to those with bulimia nervosa.

Compulsory Treatment

The use of compulsory treatment is on the rise. A recent Freedom of Information request in the UK has demonstrated that nationwide, there has been a 256% increase in the use of the Mental Health Act for patients with anorexia nervosa over the past five years (Sly, 2015). Carney et al.
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(2007) identify three main indicators associated with the use of compulsory treatment: the number of previous treatment episodes, the complexity of their condition, and the current health risk (typically measured by BMI). These indicators can be seen to closely link in with the clinical factors associated with patients diagnosed with SE-AN. Compulsory treatment in the management of seriously-ill patients is used when their anorexia is “life threatening and associated with core features of denial of illness or thinness to a degree that the use of involuntary legal commitment may be appropriate” (Watson, Bowers & Andersen, 2000). The use of compulsory treatment highlights a power imbalance and a lack of therapeutic alliance. This can be magnified due to the fact that the majority of patients placed under a legal restraining order have entered treatment as an informal (non-compelled) patient (Ramsay et al., 1999). Those with SE-AN are often requested to attend treatment informally, and once within a residential program they become “trapped” there if and when clinical staff deem it necessary for treatment to be compulsory. It is perhaps no wonder then that many such patients stop co-operating with the treatment they are prescribed, often leading to a protracted battle of wills between patients and clinicians.

However, the decision to use compulsory treatment is not taken lightly, and is used as a last resort. The aims of such a treatment approach are typically to achieve medical stability, and what limited data there are tend to suggest that these aims are met. The short-term outcomes of compulsory treatment outcomes have been found to be largely comparable to those of voluntary patients (Yager & Anderson, 2005; Watson, Bowers & Andersen, 2001). With these outcomes in mind, it is also worth remembering that the patients receiving compelled treatment would have been otherwise lost to treatment. The long-term benefits of compelled treatment are marginal, but at least the patients are kept alive with the chance of recovery still there. This approach, which essentially delivers patients from risk of harm to a low, if medically stable, weight, does facilitate the patient with AN to survive, while keeping the patient comfortably away from the much-feared normal body weight.

Compulsory treatment over a long period leads to “institutionalization.” When providing second opinions for patients who have been compulsory detained for years, a number of patients have quietly asked me to not challenge their detention. The only world the patient knows is the hospital. Frequently, the nurses can’t tolerate them, claiming they undermine the treatment of acutely-ill patients. When the time comes for the stabilized patient, though at low weight, to leave, they undermine the discharge, usually by overdose or other self-damaging behavior. A graduated response to a local apartment with the patient continuing to attend the unit as a day-patient gives them a halfway house to maintenance. It is a slow and expensive process requiring intense practical skills groups and motivation enhancement therapy. It is frequently unsuccessful.
“Compulsory Recovery” Treatment

Compulsory treatment is almost universally used to restore medical stability to SE-AN patients. The previous section has highlighted that although this approach does achieve these aims, it also furthers the expectation of those with SE-AN that the perpetuation of low weight is all that is achievable—and all that is expected—from treatment. It could be said that it “enables” the illness to flourish while keeping the patient safe from severe medical harm.

One recent intervention developed by the first author is “compulsory recovery” treatment, the central tenet of which is to provide a “last chance” for patients at high risk of developing SE-AN. The treatment sits between regular treatments for anorexia nervosa and those that are for chronic anorexia.

The intervention is for patients at a medically dangerous weight who have already experienced a number of failed treatment episodes, including treatment under a Mental Health Act restriction order. All patients on the compulsory recovery program have had an illness duration of less than ten years, and the view held by experienced clinicians is that unless they responded to treatment on this occasion, they would become classified as SE-AN. At its core, this is a calculated clinical attempt to prevent the transition from anorexia nervosa to SE-AN.

Compulsory treatment for anorexia nervosa is usually focused on weight gain and provides little psychotherapeutic input for the patient. Weight targets are typically low, for example, a BMI of around 15. “Compulsory recovery” treatment differs in that target weights for patients are set at BMI 20, and patients receive intensive psychotherapeutic input throughout their treatment. Any post-treatment weight loss is a criterion for rapid but brief readmission to the inpatient unit. The manual states that readmission will occur if presenting weight is one gram below BMI 20 on two occasions: weight was restored to a kilogram-wide band between BMI 20 and BMI 20 plus 1kg.

The therapy is an intensive mix of practical therapies, CBT and other psychotherapy groups, and one-to-one therapy of mixed counseling and focal interpretive models. These characteristics of compulsory recovery ensure that this is not a pure refeeding exercise, but rather an intensive therapeutic program with disciplined compulsory weight gain structured into it. Patients were discharged to a community eating disorder team on a compulsory community order again requiring weight maintenance.

A pilot study showed initial beneficial results. Seven patients, all under 25 years old and with an average of eight years of illness were treated. All had had previous treatment under the Mental Health Act. All had poor quality of life, social exclusion and isolation, and had failed to reach their personal potential. All were admitted to the inpatient unit on a legal order because the referring doctors judged that they were a danger to themselves.
Most patients were referred to their target weights with a progressive oral diet, beginning on a liquid diet but then transferring to normal solid food. The diet progressively increased from 700 to 3000 kilocalories a day. Two patients needed initial naso-gastric feeding, with slow transfer to solid food, which on a few occasions was under restraint.

All received a full therapy program, involving one-to-one therapy using insight-directed techniques. There was a broad group program of nutritional counseling, practical treatments, including clothes shopping, food preparation, and socialization including evening social events. They had anxiety management treatment, and body image therapy using a mirror, and practical exposure including swimming. Family therapy or couple therapy was provided but not compulsory but they were required to attend the group program. If a patient did not want to address family issues directly—perhaps because of abuse—psychodrama therapy was offered instead.

The initial response to treatment was fear with occasional marked sympathetic discharge, but no more than is common when a patient with anorexia nervosa is referred. Nonetheless, there was emotional distress and behavioral avoidance. At times the patients needed one-to-one supervision. Some with a history of self-damage began to cut.

Such a treatment is only possible if all the key staff have agreed that this admission was the last chance before the patient moved from anorexia nervosa to SE-AN. The multidisciplinary team (MDT) agreed all components of the treatment together. At times, decisions went to a vote and the first author had no greater voting rights than other staff members. The nursing staff was at the brunt of the treatment but felt empowered by their authority in the MDT. Further, all staff agreed to be bound by MDT decisions even if it wasn’t their preferred treatment choice. This reduced staff splitting.

Once normal weight was gained, the therapeutic efforts were intensified and the patient was prepared for transfer to their local community eating disorder team. In the pilot study, all patients on discharge required readmission. The threshold for readmission was deliberately symbolic and set at one gram below target weight on two occasions, as measured by their community team. If a more reasonable weight had been chosen, say 500g, it was felt the patient would have immediately reset her target by that amount while avoiding readmission. The average number of readmissions in the pilot was three for an average of six days. One patient had significant self-damaging behavior (SDB), four had cutting, and six had self-damaging thoughts. Two patients could not get to their target and further pressure from the staff to achieve this was felt to be unhelpful. They were withdrawn from the study, becoming ill again, and are now SE-AN. Two further patients, though reaching a normal weight, became so distressed that they too were withdrawn and became SE-AN. Of the three remaining, all initially held their weights. However, one was
removed from her community order by her local psychiatric team against the author’s advice and dropped her weight to BMI 18. The other two patients held their discharge weights.

This approach is expensive but for a minority represents a last hope of recovery. By being forced to go to a normal weight, the weight phobia can be addressed with intense therapy. The return to a normal hormonal structure seems to assist this process. This approach is a positive experience for some, although future robust research is required to see how the course of illness is affected by “compulsory recovery.”

Future Research

Treating those with SE-AN is a challenge for clinicians, who need to work with complex cases despite a clear sense of evidence guiding them. Future research should concentrate on means to enhance the outcome for those patients diagnosed with SE-AN. The work by Touyz et al. (2013) has provided a foundation of evidence, but foundations need to be built upon, and rapidly so. Further examination of the efficacy of SSCM and CBT-AN would enable the development of an evidence base from which we could more confidently respond to the needs of SE-AN patients. Clinicians sorely need this evidence to guide their work with this population. The Touyz study reported low dropout rates which suggests that a focus on quality of life rather than target weight was more acceptable to SE-AN patients. Future research may wish to consider other means by which to galvanize the development of therapeutic alliance with this population, to enhance engagement and maximise treatment outcome. Long-term follow-up work is also required for the course of illness of these patients receiving such treatment. The use of compelled treatment may be contentious and controversial at times, but for some patients, this may be the best option, as highlighted by the compulsory recovery section earlier. But clinicians should not have to follow this course blindly, without knowing what forms of compulsion to use, when, and on whom. This is a largely ignored aspect of research in this field, and requires urgent examination. The long-term course of illness and health service usage of patients receiving such treatment is an important area on which to focus.

Conclusion

The recalcitrant psychopathology of anorexia nervosa, combined with a lack of early vigor in initial treatment for the illness, ensures that many patients over the course of time are further classified as SE-AN. Until recently, in the eyes of many, patients with SE-AN have been beyond any reasonable chance of recovery, but this chapter has elucidated that there is always hope. The possibility of recovery from SE-AN is ever-present, yet it may take many treatment episodes and varying new treatment approaches to maximize
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these. The emerging treatment approaches identified in this chapter move the primary, fear-inducing emphasis away from weight targets and towards the person-centered identification of aspects of quality of life that the patients themselves want to identify. This is a crucial aspect of engaging patients with treatment, a foundation from which meaningful change can be made. An opposite form of approach is the stance of “compulsory recovery.” This is a last chance, designed to prevent the descent into SE-AN. This radical, perhaps controversial, approach aims to proactively engage anorexia nervosa during a treatment episode that is designed to get the patient to a physical and psychological place of safety. This is in direct contrast to the inadvertent maintenance of anorexia nervosa that is typified by many compelled treatments and which promote a life-long cycle of revolving admissions and discharges to and from intensive treatment. As a preventative approach to SE-AN, this is a tool at the disposal of the proactive and assertive clinician. For those who are already diagnosed as SE-AN, the best option at this stage would seem to be a collaborative treatment involving aspects of both CBT-AN or SSCM.

References


A New Approach to Diagnosis and Treatment of SE-AN


Managing Severe and Enduring Anorexia Nervosa


What is Palliative Care?

Historically, palliative care has been synonymous with end-of-life care, associated primarily with treatment modification designed to address the specific needs of terminally ill patients. Emerging in response to the enormous scientific advances of the 1960s and 1970s, from which maintenance of vital function through regular implementation of temporary life-saving procedures, such as dialysis and ventilation, was made possible. This approach sought to temper the “medicalization” of the dying process through the identification of a holistic response to the components of suffering, including the psychosocial and spiritual needs of the patient, in addition to their physical needs, unique to patients and their families.

This approach remains especially relevant in the present day, as confirmed by a study (Heyland et al., 2006) in which seriously ill patients and their families endorsed the following components as most important to end-of-life care: (1) honest communication with and trust in physician; (2) relief of pain and other symptoms; (3) establishment of care plan enabling discharge to home; (4) maintenance of cognitive function as necessary for completion of life tasks; and (5) avoidance of caregiver burden, particularly through cessation of life support once chances of recovery are minimal.

However, as the palliative care movement has developed, so too has its scope. As conceived today, palliative care encompasses the provision of multimodal, highly personalized treatment designed to improve quality of life when symptom-based approaches have proven ineffective or otherwise undesirable. Foundational attributes (Ferris, 2002) of this extended definition include care, implemented regardless of imminence of death, that is: (1) patient and family centered; (2) knowledge-based and collaborative; (3) accessible, safe, and effective; and (4) ethically administered, particularly as regards patient autonomy, beneficence, nonmaleficence, truth telling, and confidentiality.
Is Palliative Care Appropriate for SE-AN Patients?

The nature of anorexia nervosa involves behavior that is potentially life-threatening, i.e., prolonged food refusal accompanied by significant weight loss and nutritional compromise. Moreover, as noted by the psychoanalyst, Hilde Bruch, one of the first clinicians to provide detailed descriptions of her clinical experience in treating patients with anorexia nervosa in North American literature: “On principle, anorexic patients resist treatment” (1973). The synchronous expression of this potentially-fatal, deeply-entrenched, and treatment-resistant behavior gives rise to an ethical conundrum: at what point, if ever, should patient autonomy be compromised and compulsory refeeding initiated? Those who view extreme food refusal as a conscious choice argue against the implementation of forced treatment. However, these individuals fail to appreciate the context of serious mental disturbance in which anorexia nervosa occurs; in many cases, the disorder develops a life of its own, so consuming the afflicted individual that they lose the capacity to render informed judgment or to appreciate the reasonable consequences of such judgment. Recovery, when it occurs, is typically in the first 12 years after onset of illness, with reduced likelihood of recovery after this period (Ratnasuriya et al., 1991).

In dealing with a severely ill anorexic patient, the experienced clinician must consider their legal responsibility to provide life-saving treatment against the potential ramifications of treatment imposition in the absence of clear empirical evidence for its long-term benefit. Complicating this decision is the fact that risk of death is usually related to medical instability, the timing of which is difficult to predict. Given these circumstances, several dimensions, including (1) patient competence, (2) the potential long-term benefit, if any, compared with the likelihood of iatrogenesis given treatment imposition, and (3) the imminent risk of death, must be taken into account when considering a paradigm shift from more aggressive, symptom-based treatment to a quality-of-life-based, palliative care approach. The final decision must reflect careful consideration of concepts central to health care ethics: beneficence, the potential for improvement; and non-maleficence, the likelihood of doing harm.

What Does Palliative Care for SE-AN Patients Look Like?

**MEDACT, A Program to Treat SE-AN**

MEDACT, which stands for Modified Eating Disorder Assertive Community Treatment, was developed in 2005 at the Toronto General Hospital to meet the needs of chronically ill, treatment resistant patients with eating disorders, a group that tends to be “ orphaned” by the eating disorder treatment system. This is a group of individuals who have been through multiple hospital symptom-based treatments and no longer wish to engage in this treatment approach. The program was modeled after the
Assertive Community Treatment (ACT) approach to the care of individuals with serious and persistent mental illness, usually psychotic illness, such as chronic schizophrenia. ACT is an intensive and highly integrated approach for community mental health service delivery and typically serves outpatients whose symptoms of serious mental illness result in impairment in several major areas of life, including work, relationships, independent living, finances, and physical health. The ACT model is typically characterized by non-institutional interventions (i.e., home visits) focused on psychosocial rehabilitation and independent living, an integrated interdisciplinary team approach, and an open-ended commitment to care for as long as an individual is in need of such care (Dixon, 2000).

The MEDACT program currently operates four days per week and provides community-based care for around 30 patients at any one time. Patients are admitted and stay in the program for as long as they need its support. There is no predetermined “discharge date.” Many of the current cohort of patients have been in the program since its inception and will likely be in it for the rest of their lives. Patients will leave the program because they improve to the point that they no longer need the support of it, move too far away to be able to be reached by public transportation, or die; five individuals in the program have succumbed to their illness. On rare occasions, individuals repeatedly fail to keep appointments or cease contact with staff altogether and have to be discharged from care. The offer to re-engage at a later time is always made.

The specific goals of the program are: (1) to provide timely, client-centered individualized community-based support for individuals with SE-AN, focusing primarily on quality of life issues (rather than on changing disturbed eating behavior), such as vocational training, housing support, and enhancing social supports; (2) to facilitate medical stabilization utilizing a shared care model through on-site collaboration with family physicians; and (3) to reduce the duration of hospitalizations and recidivism rates by enhancing continuity of care and facilitating transition back into the community. In contradistinction to most eating disorder programs, the success of MEDACT is not measured by how much weight an individual has gained or whether they cease binge eating and purging, but rather on an improved quality of life while still having an eating disorder and an ability to be maintained in the community.

The program is staffed by a part-time psychiatrist and 0.8 full-time equivalent (FTE) nurse, occupational therapist, and dietitian. The psychiatrist monitors psychotropic medication and consults with family physicians on the ongoing psychiatric and medical care of patients in the program. All other staff provide psychosocial support plus discipline-specific interventions. For example, the nurse deals with the many medical problems that these patients struggle with, and often accompanies patients to medical appointments, at the same time educating family physicians and specialists on the appropriate medical care for patients who are
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seriously ill with eating disorders. Having this support has increased the number of physicians in the community willing to take on the care of these individuals. The dietitian focuses on nutritional interventions for those patients who request this or who the staff feel could benefit from such interventions. These include developing meal plans, providing meal support, accompanying patients while they go grocery shopping, and cooking meals with individuals in their homes. The occupational therapist addresses issues such as vocational retraining and supporting individuals in receiving financial assistance from various government agencies. The clinicians spend virtually all their time in the community, meeting patients where they live or in their neighborhood, depending on the degree of disability from their illness. Some patients are too medically unstable to travel so the staff meet with them in their homes, or in some instances, palliative care facilities. Staff rotate meeting with patients, usually on a weekly basis; all staff see all patients on a rotational basis. This facilitates the care of the individuals in the program as all patients have access to the discipline-specific skills of each staff. This arrangement also helps support the staff as each staff member knows each patient and can support each other in providing care. It is noteworthy that all of the current staff have worked in the program since its inception; there has been no staff turnover. Despite the difficult challenges that such patients present to clinicians, this is a reflection not only of the commitment of the staff but also that becoming intimately involved with such an group of ill patients over many years can be professionally rewarding.

The mean age of patients who have been treated in the program is 31 years, 87% are single, and over 95% have anorexia nervosa (the remainder are diagnosed with bulimia nervosa or an eating disorder not otherwise specified [EDNOS]). The average duration of illness for this group is 15 years. As expected, the group has high rates of comorbidity, with close to 50% having a mood disorder, 60% an anxiety disorder, and 30% a substance use disorder at the time of admission to the program. All patients in the program have had multiple hospital admissions at specialized eating disorder centers in Toronto and in some instances elsewhere, including the United States. In addition, most have had a number of inpatient hospital admissions or intensive outpatient interventions for treatment of comorbid conditions, most commonly substance abuse, depression, and post-traumatic stress disorder (PTSD), or medical admissions for treatment of medical complications of their illness. On objective measurements of quality of life, these women are as disabled and impaired by their illness as women with chronic schizophrenia (Kerr et al., 1992).

Case Study: Ms. A and the Concept of a Good Death

Death is one of the attributes you were created with; death is part of you. Your life’s continual task is to build your death.

Montaigne
A palliative care approach is based on the concept of a “good death.” The principles of a good death were identified by British researchers more than a decade ago (Smith, 2000; Neuberger, 2003). These include:

1. To know when death is coming, and to understand what can be expected.
2. To be able to retain control of what happens.
3. To be afforded dignity and privacy.
4. To have control over pain relief and other symptom control.
5. To have choice and control over where death occurs (at home or elsewhere).
6. To have access to information and expertise of whatever kind is necessary.
7. To have access to any spiritual or emotional support required.
8. To have access to hospice care in any location, not only in hospital.
9. To have control over who is present and who shares the end.
10. To be able to issue advance directives which ensure wishes are respected.
11. To have time to say goodbye, and control over other aspects of timing.
12. To be able to leave when it is time to go, and not to have life prolonged pointlessly.

These principles should be applied in considering the care of patients with SE-AN for whom a palliative care approach is taken. They were certainly the guiding principles in determining the approach in the following case.

Ms. A, a woman diagnosed with anorexia nervosa in her early 20s, was a patient in MEDACT for a number of years, with numerous inpatient treatments during that period for refeeding and medical stabilization. Palliative care emerged as a treatment option for Ms. A when, after more than ten years of continuous, intensive treatment—including ten inpatient hospitalizations, totaling almost four years in duration—she developed significant medical comorbidities including a near-fatal infection and ischemic bowel requiring surgical resection. Acknowledging continued deterioration despite insertion of a permanent G-J tube and the patient sabotaging the refeeding process, which rendered futile all attempts at weight recovery, Ms. A’s parents, her eating disorder psychiatrist, and the rest of her hospital treatment team sought consultation with a palliative care physician and hospital bioethicist. These discussions led to the decision to acquiesce to Ms. A’s wish to terminate refeeding and to leave hospital and return home. When asked to reflect on this decision in an interview conducted a year after her daughter’s death, Ms. A’s mother explained:

A had almost died many times . . . I mean, they knew her in all the emergency wards in the major hospitals here . . . Even when we sent her for refeeding, she relapsed . . . And she didn’t want to give up her anorexia . . . So instead of abandoning her because she was not going
to get better, her eating disorder psychiatrist who had treated her for many years said to her, “OK, A, we’re going to help you to try and live with the disease rather than trying to recover from it.” And that’s what palliative care is: it’s just part of the trajectory of living with the disease.

She also described the benefits of electing for a quality-of-life-based approach, saying:

Palliative care was a gift that was given to me. It was a time when I could reconnect with my daughter after many years of being alienated from her, a time I could show A my love and she was open to accept it. Because we didn’t react to her—if she didn’t want to eat, she didn’t have to eat—there wasn’t that anxiety, and the positive atmosphere and sense that we were all in this together opened up the opportunity for her to accept our help living with the illness.

Ms. A’s parents continued to endorse a palliative care approach even when further decompensation necessitated an extension of this quality-of-life-based treatment to include components of end-of-life care. In the aforementioned interview, Ms. A’s father emphasized the sense of dignity afforded to his daughter through the provision of self-determination in the context of a compassionate, supportive environment, saying:

Palliative care meant giving the opportunity—maybe the last opportunity—for A to choose. If one remembers the cliff and getting to the cliff, it gave her the opportunity to not only think abstractly but in concrete terms that there’s still, if she wanted, the possibility of trying to recover again. It always left the door open until the last moment.

[Following cessation of tube feeds] A found a somewhat new strength in the fact that she was listened to and accepted. Unlike in the very depressing, negative atmosphere of the hospital, A knew that she was surrounded by love and warmth . . . And she appreciated the sensitivity, the empathy, the trying to understand her better and help her as much as possible. She appreciated it until the very end.

Conclusion

Of those with adult anorexia nervosa, approximately 15–20% are treatment-refractory (Touyz et al., 2013). In addition to being highly resistant to symptom-based intervention, these patients demonstrate significant rates of medical comorbidity (Arkell & Robinson, 2008), high levels of disability (Treasure et al., 2001), and the highest mortality rate of any psychiatric cohort (Steinhausen, 2002). In response to this globally
poor quality of life, some clinicians have advocated a quality-of-life-based, palliative care approach for these SE-AN patients, up to 18% of whom will die (Williams et al., 1998), usually in acute care settings.

In some cases, such as that of Ms. A, this approach is appropriate and is most in keeping with the ethical pillars of beneficence and non-maleficence. That being said, a number of criteria must be met before informed, expert clinicians can consider a paradigm shift away from symptom-based treatment. Patient competence must be considered, as must the potential consequences of compulsory refeeding, including the potential rupture of the therapeutic alliance, particularly in the case of medical instability and possible death. Moreover, family members should be involved in the decision to pursue a less symptom-based approach as well as supported (individually and in conjunction with the patient) through its eventual implementation.

Severe chronic anorexia is best treated by an experienced multidisciplinary team, with input from experienced clinicians, including those trained in bioethics and in palliative care. Unlike patients with only physical terminal illnesses, patients with anorexia nervosa also have a mental illness. A further complication is the impact of low body weight on cognitive function. In the Minnesota studies, normal volunteers were systematically starved over several months. Although none of these subjects initially suffered from anorexia nervosa, as they began to lose weight they developed anorectic patterns of eating, with preoccupation with food, bingeing, poor concentration, reduced libido, reduction in outside interests, social withdrawal, and apathy, and they inaccurately perceived themselves to be overweight. Such perceptual abnormalities may lead to patients overestimating the width and size of their own faces by over 50% and reflect the impact of starvation on the brain. In most patients, these features disappear with weight restoration. This raises important complex issues about the ability of patients who reach a very low body weight to give or withhold consent from treatment as a result of their mental disorder. Therefore, the decision to adopt a palliative care approach for anorexia nervosa must be made on a case by case basis, ideally after consultation with bioethicists and palliative care experts, and with the full consent of substitute decision-makers (parents, spouse, etc.). Such an individualized patient- and family-centered approach will ensure that the physician is upholding the most important element of the Hippocratic Oath, “primum non nocere” (first, do no harm).

References

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Treating Males with Severe and Enduring Anorexia Nervosa Different to Females?

Theodore E. Weltzin

Although males conservatively make up approximately 10% of anorexia nervosa eating disorder patients, data suggest that rates of eating disorders in males are increasing, with some studies suggesting as many as 25% of patents with anorexia nervosa are male (Raevuori et al., 2009; Hudson et al., 2007). Given this trend toward gender neutrality from a prevalence standpoint, we can anticipate that most likely a quarter to a third of patients will continue to be significantly ill in terms of their eating disorder and this subgroup of persistently ill males will have severe and enduring eating disorders (SEEDs) (Bean et al., 2004; Woodside & Kaplan, 1994). This chapter will not cover treatment issues previously addressing the many common features of the treatment of severe and enduring anorexia nervosa (SE-AN) for both females and males, but rather will highlight differences in clinical presentation and symptoms expressed more commonly in males than females that inform the treatment process. These characteristics include increased rates of eating disorders in gay and straight men, body image concerns, including an increase desire for musculature in males, and excessive exercise as a core behavioral manifestation of anorexia nervosa. Other factors that may increase the risk of developing an eating disorder in males include mood disorders and a history of childhood adversity, which is similar to women, as well as alcoholism and psychotic disorders that are more likely to occur in men (Johnson et al., 2002; Striegel-Moore et al., 1999). It is important to underscore that males with mental illness, including eating disorders, are less likely to recognize that they have a problem, less likely to be diagnosed or identified as having a problem by professionals, less likely to seek treatment for mental health issues (Addis & Mahalik, 2003), and less likely to be referred for specialty care. Furthermore, the number of males who do seek treatment for anorexia nervosa is consistent with earlier estimates of the prevalence of males with eating disorders, with 10% of patients utilizing eating disorder treatment services being male. Also, males who did seek treatment services tended to receive a shorter duration of treatment than females seeking eating disorder treatment (Striegel-Moore et al., 2000).
Therefore, this chapter will also review factors affecting treatment and recovery, including increased stigma, both perceived and real, for males with eating disorders, misperceptions concerning males with eating disorders in our society, reduced illness recognition for those with eating disorders and health care providers, and reduced access to care.

**Case Study 1**

Ray is a 25-year-old high barista who admitted to inpatient treatment for depression with suicidal ideation. His eating disorder was characterized by restrictive eating alternating with binge purge behavior up to five times per day. He is 5 foot 4 inches tall, weighing 102 lbs./BMI 17.5, and presents with malnutrition and osteopenia. Ray presents with an extensive history of eating disorder behavior, beginning at age 19, that includes bingeing, restricting, a history of using marijuana and ethamphetamine to inhibit appetite, as well as diet pills. At age 16, Ray also attempted suicide, which was triggered by his parents finding out that he was a homosexual. Ray was previously treated for substance abuse, however, he continues to drink alcohol multiple times a week and reports that when not drinking his binge purge behavior increases. He is worried about weight gain and feels that he will not be attractive if he gains weight.

**Sexuality**

Although the majority of males with anorexia nervosa are heterosexual it is common for gay males to seek treatment for eating disorders. For example, compared with lesbian women, homosexual males not only have increased rates of eating disorder diagnosis compared to heterosexual men but also score higher on ratings of eating psychopathology (Yean et al., 2013; Russell & Keel, 2002). Compared to heterosexual males, homosexual males not only have more body image concerns (Siever, 1994) but also score higher on ratings of eating psychopathology and body image concerns, media influence on idealized body image, and body-image-related anxiety (Carper, Negy & Tantleff-Dunn, 2010). In addition, gay males experience higher levels of peer pressure to maintain a particular body type than do straight males, and higher levels of body dissatisfaction may account for higher levels of disordered eating (Hospers & Jansen, 2005). For gay or bisexual men, a history of childhood sexual abuse was not predictive of anorexia nervosa, however, the risk of bulimia nervosa was increased in these groups (Feldman & Meyer, 2007). Factors increasing the risk for developing an eating disorder in heterosexual and gay males may including an increase in feminine or masculine self-image (Murray et al., 2013; Meyer, Blissett & Oldfield, 2001) and for younger gay men, a history of being overweight (Boisvert & Harrell, 2009). Gender identity disorders may also increase the risk of eating disorders (Hepp & Milos, 2002; Surgenor & Fear, 1998).
Body Image and Muscularity

Not surprisingly, evidence indicates that men are as concerned about body image as women, resulting in methods for systematically rating body image concerns and perceptions (Edwards & Launder, 2000). However, unlike most women with anorexia nervosa whose preferred body image is thin, men with anorexia nervosa’s most commonly preferred body image is typically muscularity or overvaluing increased muscle definition very commonly in the abdominal region. Several factors that contribute to an abnormal desired or “idealized” body and body image distortion in males include the media, cultural changes leading to unrealistic expectation of male body image and muscularity, and body building (Leit, Gray & Harrison, 2002; Brownell & Napolitano, 1995). Data support that exposure to idealized images in the media increases symptoms of anger and depression in males as well as reduced self-esteem (Hausenblas et al., 2013). The results suggest that men engage in activities that increase their muscularity because they perceive muscularity will enhance their feelings of masculinity and confidence while improving their attractiveness. In an experimental study, a computerized body image assessment was used with four groups of men: anorexia nervosa, bulimia nervosa, one athletic nonclinical sample, and one nonathletic nonclinical sample that was age matched to the clinical samples (Mangweth et al., 2004). The test allowed participants to “morph” a computer image using ten levels of muscularity and body fat to depict four body types: the participant’s own body, his ideal body, the body of an average man in his age group, and the body image women would prefer. Although there were few differences on the muscularity indices, there were significant differences in the body fat indices, wherein the men with anorexia nervosa and bulimia nervosa perceived themselves as almost twice as “fat” as they actually were.

Case Study 2

John is a 20-year-old college student studying engineering who was admitted to the hospital after the university he was attending placed him on medical leave due to increasing weight loss and bradycardia associated with restrictive eating and compulsive exercising. He is 5 foot 8-and-a-half inches tall, weighing 114 lbs./BMI 17.5 and presents with a heart rate of 38 bpm, osteopenia, and low levels of testosterone. John presents with a five-year history of anorexia nervosa, restricting type, which includes symptoms of compulsive exercising, reportedly walking up to three hours a day and restricting food intake to only fruits and vegetables. John was living alone in a college dorm and reports having no friends and finds that his mind is preoccupied by body, weight, and shape. Further, he reports having no coping skills besides exercising or school work. John reports being overweight as a teenager, approximately 180 lbs., and reports
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a history of being teased in school. He reports that his temperament growing up was shy.

Excessive or Obligatory Exercise and Athletics

Males with eating disorders frequently engage in problematic exercise (Brewerton et al., 1995) with one study finding that as many as 84% of eating disordered individuals have a lifetime prevalence of problematic exercise (Davis et al., 1994). Compared with women, men are more susceptible to elements of excessive exercise, such as a lack of control, increased tolerance, and reduction in alternative activities. Signs of excessive exercise include highly structured and repetitive exercise routines that tend to focus more on endurance activities, most commonly running. Patients will often engage in exercise rather than spend time with family, attend school, or work. Furthermore, males with eating disorders will commonly continue to engage in exercise even when injured, while underweight, and in treatment, often against the recommendations of the treatment team. They will also exhibit increased emotional distress when exercise is limited. Males with eating disorders who have a significant exercise component typically describe two factors that may increase their risk of developing an eating disorder. First, they reduce food intake incrementally over time, to the point of very low caloric intake and avoidance of fats and often carbohydrates. Second, exercise activities are not aimed at maintaining strength and muscle mass, rather there is an increase in time spent in calorie-burning activities. Both activities will accelerate inadequate nutritional intake and weight loss in patients with anorexia nervosa. The focus on body image and muscle definition is achieved through reduced body fat rather than increased muscle mass. Attempts at increasing food intake, and associated fears of increasing body fat, can trigger exercise behavior or purging. Athletes are another high-risk group with specific treatment needs and challenges for males, especially sports that require low body fat or extremes of weight loss, represent a risk for developing disordered eating. A Norwegian study looked at elite athletes and found that the rates of eating disorders were twice that of the general population in males, and “anti-gravitation” sports, such as high-jumping and pole-vaulting, seemed to have a particular increase for rates of eating disorders (Sundgot-Borgen & Torstveit, 2004). Triathletes also seemed to have an increased risk for eating disorders as determined by increased scores of abnormal eating (Di Gioacchino De Bate, Wethington & Sargent, 2002). At least one study in male cyclists found that perfectionism may predict an increased likelihood of disordered eating (Ferrand & Brunet, 2004).

The Impact of Stigma on Males with Anorexia Nervosa

Obstacles for males seeking treatment for eating disorders include the misconception that eating disorders are a female phenomenon in our
society (Robinson, Mountford & Sperlinger, 2013). Stigma is a significant factor for men with eating disorders that negatively influences illness identification, public awareness, and treatment accessibility (Maier et al., 2014). Evidence shows the presence of stigma in data that the public views eating disorders as a psychiatric diagnosis more negatively than other mental illnesses such as depression (Roehrig & McLean, 2010). Males also report much less support from family, friends, school, coaches, and employers. Stigmatizing eating disorders as a female illness is not limited to society in general but also appears to be very much present with treatment and research professionals. Anecdotally, the majority of papers published typically reflect a bias toward women, typically citing sample size or not wanting to complicate the research methodology with having two genders as reasons to exclude males for research studies. Scientific meetings are overwhelmingly biased toward presentations related to women, simply passing this off as “we do not have the data.” Furthermore, it is common for professionals to use the female gender during treatment and scientific presentations that are presumably relevant to both women and men. Treatment programs are also biased toward staff and an atmosphere that is more feminine than masculine, rather than presenting a gender neutral treatment setting. Reducing gender bias with our research and treatment setting is critical to more effective treatment of males with anorexia nervosa and it is encouraging that interventions for students in the medical field can reduce stigma toward patients with eating disorders in general (Bannatyne & Stapleton, 2014).

**Treatment Outcome**

As discussed previously, the course of recovery from eating disorders is slow, with repeated admissions to treatment programs being common. Outcome research specific to males with eating disorders is very limited. Studies do suggest that men benefit from early diagnosis and treatment (Fichter & Krenn, 2003), have a similar response to treatment compared to women (Andersen & Holman, 1997; Woodside & Kaplan, 1994), and have a similar duration of illness prior to seeking treatment (Braun et al., 1999). Like women, men benefit from prognostic factors at the time of discharge including positive social supports, effective coping skills, and values-based decision-making relative to improved outcome rates (Cockell, Zaitsoff & Geller, 2004). Other protective factors for both males and females with eating disorders that have been reported are weight gain, positive self-esteem, emotional status, school achievement, and family connectedness (Croll et al., 2002).

It is important to emphasize that the majority of males who are diagnosed as having anorexia nervosa will recover from their illness. Adolescent males with anorexia nervosa receiving intensive treatment had a similar response but had a better course of illness one year after discharge
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as reflected by Eating Disorder Examination (EDE) scores. However, not dissimilar to females, roughly 25% were not much improved at one year (Strober et al., 2006). In a follow-up study of more than 1000 males and females with eating disorders, males were found to weight restore sooner, with an increased percentage of male subjects improved at the time of follow-up assessment (Stoving et al., 2011). Bean and Weltzin (2001) found that males showed significant improvement on eight subscales of the Eating Disorder Inventory (EDI) ($p < 0.001$). The most significant improvement was found on the drive for thinness, ineffectiveness, and interceptive awareness scales. These improvements remained for six months following treatment, showing that residential treatment leads to statistically significant changes in the severity of symptoms of eating disordered females. Research on outcome of treatment for males and females with anorexia nervosa at one-year follow-up found that males had a higher weight at discharge, less fasting, and better meal plan compliance (Bean et al., 2004). Medical and psychological morbidity, mortality, and working with subgroups of patients who develop enduring eating disorders are being noted in the literature (Foppiani et al., 2014). There is evidence that severity of symptoms is similar between men and women (Mehler et al., 2008), and mortality rates would also support similar severity of illness, as males are no less likely to succumb to anorexia nervosa and may have a more pernicious course in that males dying from anorexia nervosa did so earlier after discharge than women (Gueguen et al., 2012). Research suggests that males are at a double disadvantage relative to females with eating disorders. Males are reported to be less likely to receive treatment for eating disorders and those who do seek treatment are more likely to receive less care, meaning they spend fewer days in treatment (Striegel-Moore et al., 2000). These researchers found that 0.016% of males received treatment for eating disorders compared with 0.14% of females.

Treatment Strategies for Males with SE-AN

In initiating treatment of the male with SE-AN, it is important to keep in mind that data is lacking to guide us in terms of treatment outcomes or course of illness that can impact on prognosis. As a result, there is much less of an assumption that males with anorexia nervosa have previously received adequate or effective treatment. Furthermore, assuming possible negative interactions with medical professionals and people in the patient support system should also be assumed as creating a situation in which the patient may be initially guarded when entering treatment. It is often the case that males with eating disorders have had a difficult time accessing different medical and mental health professionals who feel comfortable working with males with eating disorders. Given these assumptions, it is essential from the first treatment encounter to focus on
establishing and maintaining a positive therapeutic alliance when working with males with SE-AN, as this can influence the chances of a positive treatment outcome (Stiles-Shields et al., 2013). Second, a comprehensive and cohesive treatment team that is well versed in the male with SE-AN serves several essential goals including: (1) accurate diagnosis of eating disorders and co-occurring psychiatric illnesses, as well as identification of symptoms that do not rise to the level of diagnosis but will likely influence treatment; (2) medical assessment and stabilization; (3) treatment education for patients and caregivers, and referral to the next level of care; (4) identification of nutritional goals that are realistic and support normalization of eating behavior and weight/nutritional status; (5) delivery of evidence-based psychotherapy (individual, group, and family) that takes into account specific patient characteristics; (6) collaboration with the patient’s family and support system given that at least one study suggests parents of females have achieved higher education levels than parents of males with eating disorders (Ahrén et al., 2013); (7) supporting the patient and family in adapting to changes in clinicians; and (8) providing continuity across multiple levels of care. Finally, educating the patient that treatment may be a minimum of 6–12 months, but more commonly is several years or even decades, can help.

An accurate psychiatric diagnostic formulation using the Diagnostic and Statistical Manual (DSM) criteria is an essential part of the initial assessment of psychiatric illness and particularly so with males with SE-AN. If the presenting problem is an eating disorder, determining whether the patient has anorexia nervosa (AN-R or AN-BP) as previously mentioned, males with AN-BP do have the highest risk of mortality after inpatient treatment. Current diagnostic criteria (DSM-5) specifically address more definitive diagnoses for males with anorexia nervosa and should result in less defaulting diagnostically to an eating disorder not otherwise specified (EDNOS), which can reinforce the notion of “not fitting in” in terms of seeking treatment. Furthermore, additional focus as to increased rates of organic conditions, psychotic disorders, and alcohol and substance abuse are also relevant to evaluating males for co-occurring conditions (Carlat, Camargo & Herzog, 1997; Striegle-Moore et al., 1999). Compared with females, males who present for treatment are much more likely to have been subjected to weight-based victimization, as well as more likely to have been previously overweight (Johnson et al., 2002). This increase in teasing and bullying by peers and family members concerning weight often results in low self-esteem, low self-confidence, and an increase in the risk of developing depression, anxiety, and eating disorders. Furthermore, patients who had been traumatized by teasing and bullying about weight as children were more likely to use avoidance as a primary coping skill, which can reduce treatment effectiveness if not addressed.

A comprehensive medical assessment also needs to be able to adequately assess the level of malnutrition in males and not minimize the
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seriousness of being at a low weight. The medical team also needs to be able to address emergent medical needs in males, which not uncommonly include cardiac abnormalities, including bradycardia and arrhythmias, and electrolyte disturbances, including low potassium and sodium and osteoporosis (Sabel, Rosen & Mehler, 2014). Most often, screening can be accomplished with a medical history and physical exam, followed by comprehensive laboratory testing, including a hemogram, electrolytes, chemistry panel, urinalysis, electrocardiogram, testing of thyroid hormone, as well as serum testosterone for males. It is essential that a comprehensive medical examination be a part of the initial assessment of a patient because it helps to determine the appropriate level of care as well as medical follow-up that may be necessary. The medical team also needs to monitor patients with SE-AN who continue to exhibit symptoms such as vomiting or laxative or diuretic abuse while in treatment in order to monitor and treat electrolyte abnormalities. Medical assessment can also identify other medical needs that are less acute, such as ongoing gastrointestinal complaints (for example, gastroesophageal reflux disease [GERD]), constipation, and dental concerns. Constipation is a common complaint that may increase the difficulty with normalizing food intake or abstinence from purging. Abnormalities in bone density, including osteopenia and osteoporosis, may influence recommendations for physical activity during treatment.

Nutritional goals of treatment for males with SE-AN must focus on weight gain as an essential element of recovery and therefore require a member of the treatment team to be monitoring the weight restoration progress. Nutritional intervention for males with anorexia nervosa involves stopping weight loss, restoring weight, and normalizing eating behavior. The amount of data available to guide us in determining what is normal weight or a weight that maximizes the chances of recovery from anorexia nervosa is greater in females than in males. For males, determining body weight for recovery does not have the same guidelines in terms of a return of normal menstrual functioning. Clinically, males tend to weight restore to a BMI above 21 and often it is helpful to interview family members in addition to obtaining a detailed weight history. Child and adolescent growth charts are also particularly helpful in setting weight gain goals for males with anorexia nervosa. For underweight male patients, who are susceptible to hypothalamic hypogonadism and osteoporosis, measuring serum testosterone can be an imprecise but helpful measure of nutritional status. Males in general seem to be more receptive to the impact of patient education on the negative effects of having an eating disorder, and in particular the positive impact of weight gain on testosterone levels and muscle mass given that this is often a primary body image concern even when underweight. Ideally, the amount of weight gain should be determined by a medical or dietary professional experienced with eating disorders. Most male patients with SE-AN will work with a dietician using a prescribed
“individualized meal plan” that should include adequate amounts of carbohydrates, protein, and fat as a vehicle to achieve nutritional treatment goals. Males also tend to be more fearful of fats and carbohydrates in food compared with females who are more likely to avoid calories in general. It is also important to address dietary behavior that is very rigid and limited in terms of food varieties as these typically are related to resistance to eating normally and decrease treatment effectiveness. For the adolescent male with SE-AN, if not previously tried, using family-based treatment for weight restoration can be attempted if medically stable.

During the weight gain phase, patients should be strongly encouraged to significantly limit or refrain from significant physical activity, including exercise, fitness, and any activity that is associated with the intention of increasing energy expenditure (“burning calories”) or building muscle, as this is a common response to fear of weight gain in men. Men with anorexia nervosa frequently say that they do not care how much weight they have to gain if it is muscle. Anxiety during weight gain should be redirected toward working on self-esteem and coping skills, as well as exploring antecedents of the eating disorder that often relate to body weight such as teasing or bullying. For treatment of underweight individuals, all but the most quiescent fitness activities are suspended until weight restoration is progressing satisfactorily. Once there is a positive response to nutritional and other components of treatment, fitness activities are introduced slowly and responses are observed closely. This is difficult for many individuals with eating disorders at this level of care, but particularly so for athletes or those who identify closely with athletics.

There are significant challenges in treating SE-AN when intense physical activity is a frequent and recurrent behavior. Interventions should first identify important behavioral manifestations of problematic exercise, including the frequency, intensity, and duration of physical activity, medical conditions that directly result from problematic exercise including physical injuries of overuse and abuse, and also the psychosocial impact on time management, job performance, and obligation and functioning in personal relationships. Since DSM-5 (American Psychiatric Association, 2013) identifies excessive exercise as an eating disorder symptom, anyone with an eating disorder, regardless of weight status, can exhibit excessive exercise as a symptom akin to food restriction, binging, or purging. Indicated treatment goals would be a more or less permanent cessation of problematic exercise, as extinction is certainly the goal of other eating disordered behavior such as restriction, binging, and purging. Throughout treatment and recovery stages, amount of exercise should then be monitored, and if an individual were to return to some level of problematic exercise, this would be considered a relapse. Excessive exercise behavior often needs to be addressed as part of treatment and ideally therapy should be individualized based on an assessment of the patient’s fitness beliefs and behavior. Obtaining collateral information from parents and coaches is
recommended as patients typically minimize this behavior and are often reluctant to identify exercise behavior as dysfunctional. Clinically, there are two different treatment models commonly used that are aimed at reducing problematic exercise in eating disordered patients. The first treatment model sees problematic exercise as representing a non-substance addiction, and also considers a primary behavior in which exercise and its direct impact on physical and psychological functioning leads to reward-based reinforcement of behavior. The second treatment model sees problematic exercise as a compulsive symptom aimed at avoidance or modification of some feared state or situation which in the case of eating disorders most likely relates to body image (most typically thinness in the case of females and leanness or muscularity in the case of males) and food and weight issues. Exposure and ritual prevention (ERP) for patients with co-occurring obsessive-compulsive disorder, social phobia, or food phobias, such as fear of choking on food (Simpson et al., 2013) can also be used to reduce compulsive exercise in males with SE-AN. Within the models there is significant conceptual overlap, and the presentation structure of this chapter does not imply these models are in opposition. Furthermore, while each treatment model has a unique emphasis and may suggest a differing treatment approach for a patient with an eating disorder, our experience has been that they can be used together in working with patients with problematic exercise.

With the SE-AN patients, the psychotherapist often plays the role of treatment team leader and takes ownership of maintaining treatment team communications as well as providing support, case management and individual or group psychotherapy, family therapy, and interfacing with the patients’ support network. Ideally, the psychotherapist can help patients to process and accept decisions and recommendations in a supportive way, as well as mediate conflict within the treatment team. The team approach is particularly helpful because difficulties in the therapeutic alliance may arise if therapists take on expanded roles related to nutritional goals, weighing patients, or recommendations for hospitalization or medications. In other words, it is important that psychotherapists are skilled in and enjoy individual, group, and family therapy and not assume that they can or should perform roles of other team members. Consequently, a clear, systematized approach to team member collaboration with family or non-family support providers is critical. This is a requirement for treating minors, who must have a guardian to provide informed consent for treatment. For adults, family communication provides a mechanism for explicitly articulating treatment goals, expected progress, and informed decision-making. For example, family communication is helpful when there are expected changes in the intensity of treatment or life decisions, such as moving out of the home, getting a job, or attending school. Such systematized collaboration can also reduce “caregiver burnout” for caregivers who have provided long-term support for an individual with an SE-AN.
Common psychotherapeutic themes for males include sexuality as mentioned previously. However, assuming that for the gay male sexuality is a core issue, without adequate exploration in establishing a therapeutic alliance with the patient, can lead to frustration on the part of the gay male with an eating disorder. Ideally, treatment in a group setting with other males has been beneficial and focusing on group cohesiveness, trust, processing past episodes of victimization, be it related to being teased or bullied about weight or sexuality, can create common themes in the male-only group. It is essential to understand underlying issues associated with the initiation or maintenance of problematic exercise for male patients with excessive exercise. For example, a past history of obesity or anxiety about acceptance in social situations, or anxiety concerning attractiveness or ability to perform or be accepted in intimate situations, often relates to excessive exercise behavior. Patients often report feeling forced into treatment. Engaging the male patient in treatment can be facilitated using all-male treatment groups because these allow them to see other males discussing typical eating disorder symptoms that typically have been viewed as “female” problems, while experiencing appropriate emotional expression that is identified as strength rather than weakness.

Based on clinical experience, cognitive behavioral therapy (CBT) appears to be a very useful treatment tool for working with males with all eating disorders including SE-AN. CBT gives patients a framework with which to work on eating disorder symptoms, as well as anxiety and affective disorders. Males with SE-AN tend to externalize emotional distress and, in general, are less likely to be comfortable talking about their feelings, negative experiences, or life events. Our experience working with men is that CBT provides an understandable and structured approach that both addresses externalizing tendencies and facilitates a positive exploration of thoughts and feelings. In addition, CBT helps to identify and challenge errors in thinking concerning food, weight, body image, and the drive to exercise, along with the many different triggers and thoughts and feelings associated with eating disorder behavior. In terms of approaching CBT, especially if using preprinted materials, one difference in working with males is that there are less consistent and predictable overvalued beliefs concerning food weight and shape as compared to women. Although women will frequently report feeling overweight, even when at a normal or low weight, men may not typically report this while continuing to have severe anxiety and distress concerning eating, fullness, and weight gain. It is often helpful in terms of individualizing treatment of males to approach the type of individual struggles that may not fit into our way of thinking about eating disorder treatment from a female perspective. Because of the increased likelihood of externalized coping skills and anger as a symptom of depression, a treatment team member’s ability to be comfortable with the male population can facilitate expression of thoughts and feelings as an alternative to less helpful coping skills. Family therapy is essential to
allow for appropriate and productive emotional expression and healthy conflict for patients, rather than using eating disorder behavior as the main mechanism for emotional regulation. Experiential therapy programs that include art therapy, movement, and recreation therapy, are particularly useful for work on body image and healthy nonverbal expression, team building, problem solving, and exercise issues.

Finally, the team needs to be adaptive, because for a variety of reasons, team members will change over the course of treatment for an individual. Effective and integrated communication, generated within a team-based plan, will encourage patients and family members or caregivers to experience the treatment team as continuous, cohesive, and collaborative. Disruptions should be minimized if there are changes in therapists, physicians, or dietitians. Past treatment, both positive and negative, is a form of treatment team change that most patients will have experienced. Consequently, it is important for the current treatment team to take previous treatments into account when planning the current treatment and preparing the patient for a team member change.

Conclusion

It is likely that rates of eating disorders in males will continue to increase as will, along with this, an increase in males with SE-AN. Although differences exist in risk factors and symptom expression in males with eating disorders, a growing body of evidence suggests that males respond well to treatment. However, treatment needs to be individualized for the male patient, ideally in a setting with other males and with staff experienced in working with males. Obstacles to treatment include a lack of awareness that males are at risk for eating disorders and male perception that having an eating disorder is very stigmatizing.

References


Pharmacotherapy and Novel Biological Approaches in Severe and Enduring Anorexia Nervosa
Helpful or Harmful?

Angélica Medeiros Claudino, Mara Fernandes Maranhão, and Evelyn Attia

The treatment of anorexia nervosa (AN) is a complex process that includes multi-modal interventions. Psychotherapy and nutritional support are often primary elements of effective treatment programs for AN, whereas psychotropic medications commonly play a secondary role (Hay et al., 2014; APA, 2006). The current literature is devoid of evidence-based findings that provide strong support to any specific treatment intervention for AN. The consequent lack of specific treatment guidelines may contribute to the variable outcomes for this eating disorder (ED). Although many with AN respond to available treatments and achieve recovery, a subgroup of individuals do not respond and develop a severe and enduring illness (SE-AN).

The rationale for trying pharmacological interventions in the treatment of AN is based on biological models of AN (Kaye, Fudge & Paulus, 2009; Avena & Bocarsly, 2012; Hay & Sachdev, 2011; Park, Godier & Cowdrey, 2014), on available effective treatments for other disorders and symptoms commonly comorbid with AN and for other related ED such as bulimia nervosa (BN) (Bacaltchuk & Hay, 2003), on clinical observations, and on evidence from controlled or uncontrolled studies (McKnight & Park, 2010; Hay & Claudino, 2012; Hay et al., 2014). Antidepressant and antipsychotic medications have been the primary pharmacologic classes investigated in AN, but other psychotropic agents (for example, lithium, anti-anxiety and addiction medications), appetite stimulating medications (for example, cyproheptadine, clonidine), hormones (for example, GH, estrogen), and nutritional supplements have also been tested (Birmingham, Goldner & Bakan, 1994; Hay & Claudino, 2012; Kishi et al., 2012; Misra et al., 2013).

Advances in neuroscience research over recent decades have stimulated interest in the exploration of additional and novel biological approaches in the treatment of anorexia nervosa.
Interventions, such as brain stimulation techniques, with the hope of identifying better targets for treatment and improving the existing ones, especially for patients resistant to the currently available standard treatments, such as some individuals with SE-AN.

This chapter reviews the empirical literature on pharmacological treatment for AN identified through broad-based literature searches by the authors using Medline and Scopus (up to December 2013) and additional articles published in the *International Journal of Eating Disorders* (during 2014). Additionally, a search for papers on neuromodulation in AN was conducted using Medline (up to December 2014) with an additional review of reference lists from selected papers.

An additional focus on studies that selected (as inclusion criteria) individuals with long-standing illness or that enrolled participants with a mean duration of symptoms longer than three years (identifiable in available information in publications or collected in a systematic review by Hay, Touyz, & Sud [2012]) have also been made. The features of these randomized controlled trials (RCTs) are summarized in Table 16.1.

**Pharmacological Treatment**

**Antidepressants**

The rationale behind the use of antidepressants for patients with AN has long been based on overlapping symptoms, and possibly common neurobiological roots (for example, serotonin dysfunction) (Kaye et al., 2009) among AN, depression (for example, low mood, loss of interest, social isolation), and obsessive-compulsive disorder (OCD) (for example, preoccupations, rituals). This led to initial examinations of medications with known efficacy for mood and anxiety disorders (Pizarro et al., 2014). Antidepressant drugs have also been considered as potentially useful in the treatment of AN for the appetite-stimulating and weight gain inducing properties associated with some agents in non-eating disordered populations (De Hert et al., 2011). To date, there have been a limited number of RCTs comparing antidepressants to placebo for AN, most of them of short duration (5–10 weeks) and enrolling mainly individuals undergoing inpatient refeeding programs, and these have yielded little support for their superiority to placebo in a systematic review (Claudino et al., 2006). In only one of these RCTs was there a mild but statistically significant effect in decreasing time to achieve target weight associated with amitriptyline (and for the antihistamine drug cyproheptadine) for the patients who reached target weight (33/45 individuals) during the trial (Halmi et al., 1986). The only placebo-controlled trial for which information was available regarding inclusion of participants with long-standing illness (Attia et al., 1998) did not find that the selective serotonin reuptake inhibitor (SSRI) fluoxetine added any benefit to inpatient...
Table 16.1  Randomized controlled trials (RCTs) of pharmacotherapy for anorexia nervosa (AN) including severe and enduring (SE) cases

<table>
<thead>
<tr>
<th>Authors (year)</th>
<th>N</th>
<th>Diagnosis</th>
<th>Mean Age/Years (SD)</th>
<th>Mean Duration of AN (SD)</th>
<th>Setting</th>
<th>Treatment</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vandereycken &amp; Pierloot (1982)</td>
<td>18</td>
<td>R-AN and BP-AN</td>
<td>21.5 (range 15–36)</td>
<td>1–14 years (median 3 years)</td>
<td>Inpatient</td>
<td>Pimozide (4–6mg) daily + CBT X Placebo + CBT (crossover study, 2 medication periods of 3 weeks each)</td>
<td>Effect of pimozide on weight gain tended to be significantly higher vs placebo (p=0.067), but there was no improvement in patients’ attitudes or behaviors.</td>
</tr>
<tr>
<td>Vandereycken (1984)</td>
<td>18</td>
<td>R-AN and BP-AN</td>
<td>23.3 (6.5)- group I (sulpiride-placebo sequence)</td>
<td>51.8 (49.2) months group I</td>
<td>Inpatient</td>
<td>Sulpiride (300–400mg) daily X Placebo (crossover study, 2 medication periods of 3 weeks each)</td>
<td>No significant beneficial or detrimental effect on weight or eating disorder symptoms with sulpiride vs placebo.</td>
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<td>Birmingham et al. (1994)</td>
<td>35</td>
<td>R-AN and BP-AN</td>
<td>20.6 (3.8)- zinc group</td>
<td>3.6 (2) years zinc group</td>
<td>Inpatient</td>
<td>Zinc gluconate 100mg daily X Placebo (until they achieved a 10% increase in BMI)</td>
<td>The rate of increase in BMI of the zinc group was twice that of the placebo group (p = 0.03).</td>
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<td>Szmukler et al. (1995)</td>
<td>29</td>
<td>R-AN and BP-AN</td>
<td>21.5 (0.8)—cisapride</td>
<td>39.5 (11.4) months cisapride</td>
<td>Inpatient</td>
<td>Cisapride 10mg 3 times daily X Placebo (8 weeks)</td>
<td>Gastric emptying improved significantly but equally in both groups. Cisapride &gt; placebo (p=0.02) in improving hunger and global measures. No differences in weight gain.</td>
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<tr>
<td>Study</td>
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<td>Attia et al. (1998)</td>
<td>33</td>
<td>Inpatient</td>
<td>Fluoxetine at a target daily dose of 60mg X Placebo (7 weeks)</td>
<td>Compared with placebo, fluoxetine conferred no additional benefit to the inpatient treatment (weight and psychological measures).</td>
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<td>Fassino et al. (2002)</td>
<td>52</td>
<td>Outpatient</td>
<td>Citalopram 20mg daily for 3 months X Wait list</td>
<td>No significant differences in weight gain between groups (weight gain occurred in the two groups).</td>
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<td>Mondraty et al. (2005)</td>
<td>15</td>
<td>Inpatient</td>
<td>Olanzapine mean 10mg daily X chlorpromazine mean 50mg/day</td>
<td>Observed reduction in ruminative thinking which was significantly greater in the olanzapine group. No differences in weight gain between groups.</td>
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<td>Bissada et al. (2008)</td>
<td>34</td>
<td>Outpatient</td>
<td>Olanzapine group: greater rate of increase in weight, earlier achievement of target BMI, and a greater rate of decrease in obsessive symptoms.</td>
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<td>93</td>
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<td>Fluoxetine 63.5mg (15.8) daily for 1 year + CBT X Placebo + CBT</td>
<td>All had weight restored at the start of RCT. No difference in relapse prevention between groups.</td>
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### Table

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<td>Outpatient</td>
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<td>Quetiapine treatment resulted in both psychological and physical improvements, with minimal associated side-effects.</td>
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<td>Fazeli et al. (2010)</td>
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<td>Decrease in total fat mass and extremity fat mass in the rhGH group X placebo. Groups not compared on psychological measures.</td>
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<td>Miller et al. (2011)</td>
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<td>R-AN and BP-AN</td>
<td>1. 25.3 (6.3) 2. 27.1 (7.3) 3. 25.2 (6.2) 4. 26.9 (7.2)</td>
<td>1. 5.1 (5.8) 2. 6.6 (5.5) 3. 6.3 (6.8) 4. 5.2 (4.3)</td>
<td>Outpatient</td>
<td>1. Risedronate 35mg + placebo patch 2. Testosterone 150 μg daily patch + weekly placebo pill 3. Risedronate 35mg weekly + testosterone 150 μg daily 4. Double placebo (12 months)</td>
<td>Weight did not change. Residronate increased spine (p&lt;0.001), hip (p&lt;0.02) but not radial bone mineral density x placebo. Testosterone increased lean body mass but not bone density x placebo. No added effect of combined testosterone to risedronate compared to combined placebo.</td>
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<tr>
<td>Study</td>
<td>Participants</td>
<td>Age Range</td>
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<td>Bloch et al. (2012)</td>
<td>26 R-AN and BP-AN</td>
<td>26.6 (8.9) DHEA 27.4 (7.4) Placebo</td>
<td>Outpatient</td>
<td>DHEA 100mg daily X Placebo (6 months)</td>
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<td>Both groups showed a small but non-significant weight gain by the end of six months. BMI showed a greater initial increase in the DHEA group compared to placebo, reaching a peak difference after the first four months. No improvement in BMD was detected. Change in mood severity was significantly correlated with weight change in the DHEA group only.</td>
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<td>Powers et al. (2012)</td>
<td>21 R-AN and BP-AN</td>
<td>34 (13.5)</td>
<td>Mentions “the majority of patients have longlasting disease”</td>
<td>Outpatient</td>
<td>Quetiapine mean dose 177.7mg X Placebo (8 weeks)</td>
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<td>There was no difference in outcome for any of the measures (weight gain and psychological measures) between groups.</td>
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<td>Andries et al. (2014)</td>
<td>25 R-AN and BP-AN</td>
<td>33.3 (28–38.7) years</td>
<td>15 (10.2–19.9) years</td>
<td>Outpatient</td>
<td>Dronabinol 2,5mg twice daily for 4 weeks X Placebo (crossover study)</td>
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<td>Participants taking dronabinol gained 0.73 kg (p&lt;0.01) above placebo without significant psychotropic adverse events.</td>
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Note: R-AN = Restricting-AN; BP-AN = Binge/Purge-AN; BMD = Bone Mineral Density.
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weight restoration treatment, either in terms of weight gain or psychological improvement, including mood and anxiety symptoms (see Table 16.1). In addition to the placebo-controlled trials, other small RCTs in which nortriptyline (for restrictive type SE-AN: mean duration of illness = 3.4 years +/- 3) (Brambilla et al., 1995a), amineptine (for binge-purge type SE-AN: mean duration of illness = mean 4.6 +/- 3.9) (Brambilla et al., 1995b), or clomipramine (for restrictive-type AN) (Ruggiero et al., 2001) were compared to fluoxetine reported only minor effects of the first two medications compared with fluoxetine in reduction of anxiety or ED symptoms, respectively. Another RCT that also enrolled participants with long-standing AN (as defined here) (Fassino et al., 2002)—not included in the systematic review (Claudino et al., 2006) as it did not meet the review’s inclusion criteria—tested citalopram versus a waitlist group, but its findings did not add to the previous negative results found for weight regain associated with antidepressant medications, albeit mean duration of treatment was longer (three months) in this trial (see Table 16.1).

Two trials have examined post-weight restoration effects of fluoxetine in relapse prevention during one-year follow-up and found conflicting results (Kaye et al., 2001; Walsh et al., 2006). In only one, the second and larger trial (with 93 weight-restored patients randomized to fluoxetine or placebo in addition to cognitive-behavioral therapy [CBT]), information on inclusion of participants with SE-AN is available and results did not demonstrate an advantage for fluoxetine in preventing relapse (defined as worsening of ED symptoms, weight loss, development of major clinical problems or suicidal ideation) for one year following hospitalization (Walsh et al., 2006). Although Kaye et al. (2001) suggested a potential effect of fluoxetine in relapse prevention, the study’s findings were limited by high attrition rates.

Antipsychotic Medication

Early findings from clinical trials of short duration that examined typical antipsychotic medications raised the possibility of a potential role for this class of drug to treat AN (Dally & Sargant, 1966). Vandereycken (1984) reported the increase of daily rate of weight gain with sulpiride in a crossover trial, though this result was not observed with pimozide in a similar RCT (Vandereycken & Pierloot, 1982). However, problematic adverse effects, likely associated with these medications’ variable effects on histamine, acetylcholine, and alpha-adrenergic receptors, in addition to their prominent D2 receptor antagonism, interrupted consistent research using this class of medications. Curiously, these initial studies included SE-AN (see Table 16.1) as did a six-month open trial (Cassano et al., 2003), that enrolled specifically treatment-resistant patients (N=13) with a mean of 6.3-year duration of illness and a mean BMI at intake of 15.6 kg/m² (SD = 1.2). Cassano and colleagues tested low dose (1–2mg/day)
of haloperidol as an adjunct to standard treatment (i.e., treatment with an antidepressant medication). Not only did the participants significantly regain weight to BMI 18.1 kg/m^2 (SD = 2.51) by the study’s end, but they improved in psychological measures related to their ED (for example, drive for thinness, interoceptive awareness, ineffectiveness), and overall clinical assessment scores.

AN is the only ED for which there is some empirical support for the possible utility of antipsychotic medications, including their use among treatment-resistant patients. The available evidence specifically suggests considering the atypical or second-generation antipsychotic medications (Halmi, 2013). The basis for recommending second-generation antipsychotic medication includes target of “psychotic-like” symptoms (for example, near-delusional body image perceptions and interpretation of weight), extreme anxiety, and obsessionality, features commonly observed among SE-AN patients. Additionally, the weight gain commonly observed as a side-effect of these medications when they are used in other clinical populations added to the interest in their investigation for AN (Komossa et al., 2010). Renewed interest arose in the last decade for the use of atypical antipsychotic medications to modulate serotonin or dopamine imbalances underlying the psychopathology of AN (Kaye et al., 2009) while, at the same time, take advantage of a potential wider spectrum of effects with a more tolerable adverse effect profile.

Olanzapine, a 5HT2/D2 receptor antagonist (blocks serotonin [5HT] and dopamine [D] neurotransmission at postsynaptic receptor sites) has been systematically investigated in five RCTs, and at least three of them have included SE-AN participants (see Table 16.1). Mondraty et al. were the first to study olanzapine, comparing it to chlorpromazine, in a small, non-blinded RCT that added study medication to inpatient treatment. Olanzapine was favored for its effect on reduction of ED ruminations (Mondraty et al., 2005). In a subsequent trial of adjunctive olanzapine or placebo to CBT (Brambilla et al., 2007), greater effects on weight gain and mood improvement were found only for the subgroup of patients with binge-purge type of AN. In the third study, Bissada et al. (2008) also reported that those on olanzapine showed greater reduction in obsessive symptoms, regained weight more quickly and were more likely to reach BMI > 18 kg/m^2 compared with those on placebo for ten weeks (87.5% compared with 55.6%). However, acceptance of this treatment was low as over 50% of eligible participants refused to enter the trial. Further placebo-controlled small trials testing olanzapine, for which specific information on inclusion of individuals with SE-AN was not presented in the publication, showed mixed findings. Attia et al. (2011) also reported improved rate of weight regain associated with olanzapine compared with placebo among outpatients receiving study medication for eight weeks; no other significant effect on psychological measures was identified. In contrast, Kafantaris et al. (2011) did not support the adjunctive use of
olanzapine in adolescents with AN (engaged in an ED program), and found increased fasting glucose and insulin levels at the end of the study in the group that received active medication.

In addition to these RCTs of olanzapine, quetiapine, another atypical antipsychotic medication with a similar mechanism of action (blocks D2 and 5HT2 receptors), has been tested in two RCTs in AN: one compared it to treatment as usual (Court et al., 2010) and the other to placebo (Powers, Klabunde & Kaye, 2012), with no identified improvement for weight regain and minor effects on psychological measures associated with ED psychopathology (Court et al., 2010). Again, in these trials, participant recruitment proved problematic, and fear of weight gain associated with medication use was the main reason cited for refusing the treatment in one trial (Powers et al., 2012). Amisulpride, an atypical antipsychotic medication with somewhat different receptor activity than others in the group, associated with D2 and D3 presynaptic receptor antagonism at low dose and direct postsynaptic antagonism at high dose, was compared (in low dose) to fluoxetine and clomipramine in a small trial (N=35) by Ruggiero and colleagues (2001). Investigators reported greater weight gain associated with the antipsychotic medication (Ruggiero et al., 2001). The most recent RCT using this class of medications (Hagman et al., 2011), examined risperidone (a neuroleptic drug that antagonizes the actions of several neurotransmitters) versus placebo and did not find any support for its use in an adolescent sample.

In the face of these mixed findings regarding the effectiveness of antipsychotic medications for individuals with AN (in general, not only the ones with SE-AN), two meta-analyses (Kishi et al., 2012; Lebow et al., 2013) tried to strengthen the information available regarding this class of medications and their possible benefits by aggregating data from some of these small trials; however, findings were again disappointing both in terms of weight regain and improvement of symptoms. Lebow et al. (2013) reported improvement of mood but possible worsening of anxiety, and Kishi et al. (2012) described increased adverse effects as drowsiness and sedation with antipsychotics, although attrition rates did not differ between treated groups and the placebo group. In addition, increased symptoms of binge eating have been mentioned with use of these medications (Moore et al., 2013).

**Other Psychotropic Agents**

Apart from a small four-week trial of lithium versus placebo for AN (Gross et al., 1981) that yielded some minor positive findings including weight gain, the use of such mood stabilizing agents and anticonvulsant medications did not advance as treatment options for AN. The same occurred with cyproheptadine, an anti-allergy medication with histaminic and serotonin antagonist effects, that improved the rate of weight gain
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in individuals with restrictive-type AN (only) in an earlier trial (Halmi et al., 1986), and was reported to show better results in the subgroup of patients with the severe form of illness (i.e., those with lower weights, and greater number of prior treatment failures) in another trial (Goldberg et al., 1979).

On the basis of the premise that some ED behavior (for example, binge eating) may be related to that observed in addictive disorders, that it might share neurobiological pathways (Kaye et al., 2013), and that the endogenous opioid system is involved in eating behavior, medications used to treat addictions have also been investigated in AN. Marrazi et al. (1995) examined the effects of the opiate antagonist naltrexone in the treatment of AN and BN. While the investigators found a reduction of binge-purge symptoms, the study’s small sample size (six individuals with AN) limits meaningful conclusions (Marrazzi, Bacon & Kinzie, 1995). Also, considering the demonstrated role of the endocannabinoid system in the modulation of appetitive behavior and regulation of energy homeostasis, an early trial (Gross et al., 1983) compared effects of tetrahydrocannabinol (THC, a CB1 receptor agonist) (7.5mg–30mg/day) to diazepam (as a “placebo”). Although weight gain was higher in the group that received THC, high rates of study dropout due to dysphoric reactions discouraged its use. However, a recent and possibly unique pharmacological trial (Andries et al., 2014) that specifically selected individuals with SE-AN (AN for longer than five years as an inclusion criteria), women aged 18–25, investigated the orexigenic and anabolic effects of dronabinol (a synthetic cannabinoid) in a double-blind, randomized controlled crossover study. Participants received dronabinol 2.5 mg twice daily for four weeks and matching placebo for four weeks, separated by a four-week wash-out period. Medication was well tolerated and produced modest but statistically significant increases in weight gain compared to placebo, although psychological measures associated with eating and related behavior did not change.

There is also great interest in the use of anxiety-reducing (i.e., anxiolytic) medications due to the frequency and intensity of anxiety observed in AN and reported prior to illness onset in many. Additionally, several investigators have noted shared additive genetic influences of AN and anxiety traits (Bulik et al., 1997; Silberg & Bulik, 2005; Kaye et al., 2014; Le Grange et al., 2014). Nevertheless, there is only one small pilot study examining a benzodiazepine (alprazolam) versus placebo for AN, finding no benefit associated with active medication (Steinglass et al., 2014). However, D-cycloserine, a glutamate partial agonist has been tried as an adjunct to four sessions of the anti-anxiety exposure therapy (focused on meal consumption) in a very small trial including SE-AN (Steinglass et al., 2007). The drug did not enhance any effects of the exposure therapy (which seemed promising) but the trial was not adequately powered to fully evaluate the medication’s potential for an adjunctive role.
Prokinetic agents such as cisapride have also been investigated in two small placebo-controlled trials (Stacher et al., 1993; Szmukler et al., 1995). Szmukler and colleagues (trial including SE-AN) found improved clinical measures, including perceived hunger and a global measure of change in inpatient participants, but weight gain and gastric emptying were not different in participants receiving medication compared with those receiving placebo. Cisapride was withdrawn from the market due to its increased risk of cardiac arrhythmia. Investigations of other medications such as clonidine (Casper, Schlemmer & Javaid, 1987) and growth hormone (Hill et al., 2000) did not add much to this scenery and even raised issues regarding the safety of their use as had been the case with cisapride. Of note, the clonidine versus placebo study included participants with SE-AN, but only four patients meeting these criteria were randomized, hence the study’s exclusion from Table 16.1.

Severe malnutrition combined with excessive exercising may lead to zinc deficiency in AN, and this may, in turn, possibly serve to maintain the illness through dysregulation of serotonergic and GABAergic neurotransmission, as these processes require zinc (Birmingham et al., 1994; Birmingham & Gritzner, 2006). The largest trial that examined the nutritional supplement zinc (Birmingham et al., 1994) and included SE-AN (see Table 16.1) is the only one that found a twofold increase in the rate of weight gain among those taking zinc, but no clear support emerged from previous studies (Katz et al., 1987; Lask et al., 1993).

Osteopenia and osteoporosis are serious medical complications of AN that place these patients at increased lifetime risk for fractures (Fazeli & Klibanski, 2014). Loss of bone mineral density (BMD) can occur very early in the course of AN (Bachrach et al., 1990) and be long-standing among those who remain ill. The etiology of bone loss in AN is multifactorial. In addition to nutritional deficiencies and reduced estrogen and progesterone, relative hypercortisolemia and low levels of insulin-like growth factor (IGF-1), a correlate for bone formation, are also observed.

A large volume of research investigating bone metabolism and treatment of low BMD in AN has been published to date, but studies that focus on individuals with long-standing illness are scarce (Howgate et al., 2013). In contrast with the unequivocal benefits seen in postmenopausal osteoporosis, administration of hormone replacement therapy (HRT) in AN remains controversial, with a number of previous studies that failed to demonstrate a benefit of oral contraceptive (OC) treatment on BMD in these individuals (Golden et al., 2002; Munoz et al., 2002; Strokosch et al., 2006). The use of oral dehydroepiandrosterone (DHEA) (Gordon et al., 2002; Bloch et al., 2012) and transdermal testosterone
have also failed to demonstrate consistent benefit for increasing BMD in AN after controlling for weight gain (Miller, Grieco & Klibanski, 2005). However, an RCT (Misra et al., 2011) investigating the effects of physiologic transdermal estrogen replacement (100mcg 17β-estradiol, with cyclic progesterone) on BMD in adolescents with AN was the first study to report that both the spine and hip BMD Z-scores increased significantly over time in patients treated with estrogen in comparison to placebo. This study indicates that physiologic estrogen replacement may be effective in increasing BMD for this population and should be studied as a therapeutic option in individuals with refractory illness.

Another promising pharmacologic strategy to address the underlying pathophysiology of AN includes adding recombinant human IGF-1 (rhIGF-1) to OC. A prospective, single-blinded study with 60 osteopenic adult females with AN (Grinspoon et al., 2002) reported that lumbar spinal BMD increased significantly in response to treatment with rhIGF-1 compared with placebo. However, an even greater increase in spinal BMD was seen in the group that received combination treatment with rhIGF-1 together with OC compared to placebo alone.

The use of bisphosphonates has also been considered to increase BMD in AN, especially in adults. A first RCT (Golden et al., 2005) that investigated the effect of alendronate (10 mg once daily) for the treatment of osteopenia in a group of adolescent females—that also included subjects with long-lasting disease (mean duration of illness was 25.7+/-14.6 months in alendronate group and 34.7+/-28 months in placebo group)—could not evidence greater effects of the bisphosphonate compared with placebo after one year of treatment, but there was a trend in favor of a positive effect of alendronate as the BMD in both the femoral neck and lumbar spine had increased significantly from baseline measurements by 4.4 and 3.5%, respectively. However, in a later trial, Miller et al. (2011) showed more favorable results with risedronate, either alone or in combination with low-dose testosterone (there was no added effect of testosterone to effects of risedronate compared to added placebo) on BMD in adult females with AN, in comparison to patients taking only placebo.

Despite the lack of impact of hormonal therapies on BMD in AN, there is some evidence of benefits on weight gain demonstrated in a recent meta-analysis testing the efficacy of hormone therapy versus placebo in AN (de Vos et al., 2014). Considering only the eight studies where hormones were used, this type of therapy led to a significantly larger effect of hormones on weight gain compared to placebo (although effect sizes were small to medium), but important heterogeneity found among studies warns that these results should be taken with caution. Although the majority of studies included in this meta-analysis did not focus on severe and enduring illness, these results support further investigation of hormonal therapies for this population.
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Novel Biological Approaches: Neuromodulation in AN

In the quest to develop novel treatment modalities, there is increasing interest in abnormal neural mechanisms that may contribute to the initiation of AN. The exact neural circuitry responsible for the disturbances seen in AN has not yet been fully elucidated, but there are certain regions of interest (Kaye, 2008). These regions play a crucial role in emotions, personality, and reward, all of which are thought to be important in AN (Park et al., 2014). Brain imaging studies (Uher et al., 2004; Hay & Sachdev, 2011; Park et al., 2014) suggest that AN patients have an imbalance between “bottom-up” ventral limbic neural system (involved in identifying rewarding and emotionally significant stimuli and for generating affective responses to these stimuli) and “top-down” dorsal executive function neural circuit (thought to modulate selective attention, planning, inhibition, and emotional self-control). The ventral limbic neural circuit includes the amygdala, anterior insula, anterior ventral striatum, ventral regions of the anterior cingulate cortex, and the orbitofrontal cortex, the dorsal cognitive circuit comprises (among other regions) the hippocampus, dorsal regions of the anterior cingulate cortex (ACC), dorsal regions of the caudate, dorsolateral prefrontal cortex (DLPFC), and parietal cortex. The majority of neuroimaging studies in AN found recovered and ill subjects to be surprisingly similar (Hay & Sachdev, 2011). Overall, these studies make it possible to hypothesize that AN patients have a diminished sensory-hedonic-motivational “drive” to consume food (as a consequence of a trait for aberrant ventral limbic system function) combined with enhanced inhibitory abilities (a trait for exaggerated dorsal cognitive function).

Neuromodulation is the term adopted to denote controlled electrical stimulation of the central or peripheral nervous system and implies focused stimulation of a specific region that can be used to stimulate or inhibit neural activity (Andrews, 2003). Neuromodulation techniques comprise invasive methods such as deep brain stimulation or other neurosurgical procedures, and non-invasive brain stimulation, including repetitive transcranial magnetic stimulation and transcranial direct current stimulation. Given the high mortality rates and chronic outcome experienced by a subgroup of patients with AN, neuromodulation techniques have been increasingly proposed for the treatment of severe and long-standing AN proven to be refractory to standard treatments (McClelland et al., 2013a).

Invasive Neuromodulation: Deep Brain Stimulation

Deep brain stimulation (DBS) is an invasive but reversible method of neuromodulation that has been increasingly used in the treatment of neuropsychiatric diseases that do not respond to conventional treatment. DBS is achieved by neurosurgical placement of electrodes attached to a
stimulation device that delivers a current to the specific area of the brain where the electrode has been placed. DBS has been FDA approved for use in essential tremor (1997), Parkinson’s disease (2002) and a Humanitarian Device Exemption approval in the United States for dystonia (2003) (Andrews, 2003; Albert et al., 2009). Regarding psychiatric disorders, this technique is currently approved by the United States FDA using a humanitarian device exemption for use in refractory obsessive compulsive disorder (OCD) (Food and Drug Administration, USA, 2009). In spite of the promising therapeutic potential of DBS, the mechanisms of action, the optimal targets, and the best parameters for stimulation are yet to be established (Pandurangi, Fernicola-Bledowski & Bledowski, 2012). Preclinical and clinical research suggest DBS at high frequencies induces a lesion-like effect in the target area (Halpern et al., 2008; Albert et al., 2009; van der Plasse et al., 2012), despite evidence that this might be an oversimplification. Although the effects of DBS in Parkinson’s disease patients are often described as immediate, other patient groups (for example, OCD patients) show only gradual amelioration of symptoms after prolonged stimulation, suggesting that neuroplastic changes might also underlie the behavioral effects of DBS (Bittar, 2006).

To date, very limited data exist on the effects of DBS in the treatment of AN. There are two case reports (Israël et al., 2010; McLaughlin et al., 2013), a case series with four patients (Wu et al., 2013), and a phase I pilot trial (Lipsman et al., 2013) of DBS in six patients; the results are summarized in Table 16.2. The first published case of DBS in AN (Israël et al., 2010) described a patient with comorbid major depression. The subcallosal cingulate was selected as a target, given the early evidence for its efficacy in DBS trials for depression. The patient was 52 years old when she underwent bilateral DBS electrode implantation; her severe AN, restricting subtype, began age 17. At the follow-up assessment, three years after initiation of DBS, she had required no further interventions for her ED and had maintained an average BMI of 19.1 kg/m² for over two years. More recently, Lipsman et al. (2013) utilized the same subcallosal cingulate target for their DBS trial. In both studies, improvements were identified for most patients, although relapses were also observed. An additional target, the nucleus accumbens/ventral striatum, which is highly involved in reward processing, was investigated in two studies: (1) a case series with four AN patients (average baseline BMI was 11.9 kg/m² and patients were considered to suffer from severe and refractory illness despite the fact that the mean duration of AN was 18.5 months only) (Wu et al., 2013); (2) a case report of a patient with comorbid OCD and a history of AN (BMI 18.5 kg/m² at surgery) (McLaughlin et al., 2013). These studies suggest that DBS may have potential to provide increases in BMI and a significant improvement in core symptoms and associated comorbidities of refractory and life-threatening cases. However, this procedure for AN is at its very early stages of experimental research.
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<tr>
<td>Israël et al. (2010)</td>
<td>1</td>
<td>R-AN + Treatment Resistant Depression (TRD)</td>
<td>56</td>
<td>35 years (diagnosis since age 17, with periods of partial recovery)</td>
<td>Subgenual cingulate cortex</td>
<td>Surgery performed for refractory depression. At two years, normalization of eating attitudes and weight (BMI 19.1kg/m²) preceded by a relapse (weight loss) eight months after DBS.</td>
</tr>
<tr>
<td>Wu et al. (2013)</td>
<td>4</td>
<td>R-AN and BP-AN (3 patients had OCD and 1 had GAD)</td>
<td>16.5 (mean)</td>
<td>1.5 years (average) (all had failed to respond to standard psychiatric treatment program of at least 12 months)</td>
<td>Nucleus accumbens</td>
<td>At 38-month (mean) follow-up, 65% mean increase in weight, all patients resumed menstruation, YBOCS reduced to 2, and 3/4 of patients returned to school.</td>
</tr>
<tr>
<td>McLaughlin et al. (2013)</td>
<td>1</td>
<td>AN (subtype not mentioned) + OCD</td>
<td>52</td>
<td>Not reported (patient was reported to suffer from long-lasting AN and consistently resisted to improve her food intake)</td>
<td>Ventral capsule/ventral striatum</td>
<td>DBS performed for treatment-resistant OCD. Following surgery, patients improved attitude toward food, “less bothered,” BMI reached 18.9–19.6 kg/m² in post-op period.</td>
</tr>
<tr>
<td>Lipsman et al. (2013)</td>
<td>6</td>
<td>R-AN and BP-AN (all patients except one had comorbid psychiatric disorders, with MDD and OCD being the most common conditions.</td>
<td>38 (mean)</td>
<td>18 years (average)</td>
<td>Subcallosal cingulate</td>
<td>Nine months post-DBS, 50% of patients had a significant increase in BMI vs. baseline. At six months, 2/3 improved depression and anxiety scores. One serious adverse event (seizure) followed device programming, which occurred in the context of a severe metabolic disturbance.</td>
</tr>
</tbody>
</table>

Note: R-AN = Restricting-AN; BP-AN = Binge/Purge-AN; MDD = Major Depressive Disorder; OCD = Obsessive Compulsive Disorder; GAD = Generalized Anxiety Disorder; YBOCS = Yale-Brown Obsessive Compulsive Scale; BMI = Body Mass Index.
and cannot be recommended as a therapeutic tool before being tested in sham-controlled trials where safety issues are further investigated.

**Non-Invasive Neuromodulation in AN: Transcranial Magnetic Stimulation and Transcranial Direct Current Stimulation**

Transcranial magnetic stimulation (TMS) has developed into a powerful tool that utilizes magnetic fluxes to stimulate accessible areas of the human cortex. Interest in the use of TMS as a treatment for neuropsychiatric diseases was augmented by the development of a device that could deliver rapid, repetitive stimulation (rTMS). Depending on stimulation-frequency and pattern, cortical excitability can be either enhanced (with high frequency stimulation \( \geq 5 \text{ Hz} \)) or reduced (with low frequency stimulation \( \leq 1 \text{ Hz} \)) (Esser et al., 2006; Thickbroom, 2007).

There is also initial research in the treatment of AN with rTMS. In a case report (Kamolz et al., 2008), rTMS was successfully used to treat comorbid depression in a 24-year-old patient with AN. She received three cycles of high frequency rTMS (10Hz), at 110% of the motor threshold delivered over the left DLPFC to treat her depression (total of 26 rTMS sessions) followed by eight weeks of maintenance therapy that included twice weekly rTMS sessions; a considerable increase in BMI was observed (from 12.4 kg/m\(^2\) to approximately 16 kg/m\(^2\)) after 12 weeks of rTMS.

Based on the ability of rTMS to stimulate underlying cortical areas, a pilot study (Van den Eynde et al., 2013) investigated the effects of a one-off session of high-frequency rTMS delivered to the left DLPFC in ten subjects with AN (restricting and binge/purging type). Twenty trains of high-frequency (10 Hz) rTMS were delivered, with an intensity of 110% of the individual’s motor threshold, providing 1000 pulses over 20 minutes. The results demonstrated a reduction in feelings of fullness, fatness, and anxiety. The effect on more complex behavior, such as urge to restrict or urge to exercise, could not be demonstrated. In addition, more recently, McClelland et al. (2013b) described findings from two individuals with treatment-resistant AN who received 19–20 sessions of neuronavigated, high-frequency rTMS, also applied to the left DLPFC. Patient A was a 23-year-old woman who had been treated as an inpatient for approximately 12 years while patient B was a 52-year-old woman with enduring AN of the binge/purge type (the average duration of illness was 35 years). In both cases, there was improvement in ED symptoms and mood with rTMS, and these changes persisted or continued to improve up to the one-month follow-up assessment.

Transcranial direct current stimulation (tDCS) is another non-invasive technique that delivers a weak polarized direct current to the cortex using two electrodes (an active and a reference electrode), inducing changes in the underlying neural cell membrane potential: anodal stimulation increases neuronal firing rates, while cathodal stimulation diminishes
neuronal activity. tDCS differs qualitatively from other techniques such as TMS by not inducing neuronal action potentials, as static fields in this range do not yield the rapid depolarization required to produce action potentials in neural membranes. Hence, tDCS might be considered a neuromodulatory intervention (Nitsche et al., 2008).

Existing data on the effects of tDCS in AN are derived from a pilot study (Khedr et al., 2014) that describes findings from seven individuals with treatment-resistant AN who received ten sessions of anodal tDCS over the left DLPFC. At the end of treatment, five of the seven patients improved in ED symptoms measured by the Eating Attitude Test, and Eating Disorder Inventory, and depressive symptoms measured by the Beck Depression Inventory, but in only three participants did the effects remain at the one-month follow-up. The last two patients showed little or no effects of treatment. Further research should address the role of tDCS as an adjuvant treatment for AN. The studies described are summarized in Table 16.3.

Conclusions and Clinical Implications: Are Biological Interventions Helpful or Harmful for Severe AN?

As pointed out in this chapter, the evidence for pharmacological treatment of SE-AN is still scarce. Selected samples were probably mixed in most studies in terms of age, severity, and duration of illness of participants (not always reported in publications), and subgroup analyses were not conducted to better inform on impact of treatments for this specific population. As AN is much more prevalent in women, findings also refer mostly to females. In addition, the main outcomes of interest examined in these trials are those relevant to the acute stage of illness, commonly weight-related or eating pathology measures. Next to no data are available regarding interventions aimed at preventing relapse or addressing specific needs of individuals in a chronic stage of illness. For example, reduction of comorbid psychiatric pathology that may increase resistance to treatment, or pursuing interventions that may improve general health parameters such as nutritional and medical stability, with or without weight gain, and other improvements to global functioning and quality of life, should be goals of biological interventions and better evaluated in clinical trials. In addition, it is certainly important to examine whether and how biological interventions impact on overall cognitive and emotional functioning, as well on more specific psychological aspects commonly disturbed in those with long-standing AN, including self-esteem, interceptive awareness, body image perception, etc. Moreover, predictors of treatment response need to be more systematically investigated in trials, such as severity and duration of illness, previous interventions, motivation to change, and other features.

The few controlled pharmacologic studies performed to date have focused on a range of medications, but trials were small and of short
Table 16.3: Studies of non-invasive brain stimulation for the management of anorexia nervosa (AN)

<table>
<thead>
<tr>
<th>Authors (year)</th>
<th>N</th>
<th>Diagnosis</th>
<th>Age/Years</th>
<th>Duration of AN</th>
<th>Type/Target/Protocol</th>
<th>Results/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kamolz et al. (2008)</td>
<td>1</td>
<td>BP-AN + MDD</td>
<td>24</td>
<td>4 years</td>
<td>rTMS</td>
<td>Improvement in depression and ED symptoms (less negative cognitions and weight gain). 2 phases: acute (26 sessions) and maintenance therapy (15 sessions, 2 p/week).</td>
</tr>
<tr>
<td>Van den Eynde et al. (2013)</td>
<td>10</td>
<td>R-AN and BP-AN</td>
<td>25 (mean) (range 3–30 years)</td>
<td>10 years (mean)</td>
<td>rTMS (1 session)</td>
<td>Significant reductions in feeling fat, feeling full, and anxiety on the visual analogue scale. No significant changes in mood, tension, hunger, “urge to eat” or “urge to restrict.”</td>
</tr>
<tr>
<td>McClelland et al. (2013)</td>
<td>2</td>
<td>R-AN (Patient A) BP-AN (Patient B)</td>
<td>23 (Patient A) 52 (Patient B)</td>
<td>12 years (Patient A) 35 years (Patient B)</td>
<td>rTMS (neuronavigated)</td>
<td>Patient A: no change in weight at post-treatment or at one-month follow-up; EDE-Q scores were significantly lower at post-treatment (except Eating Concern). Patient B: improvements in depression and EDE-Q scores, but no change in weight at post-treatment or at one-month follow-up observed.</td>
</tr>
<tr>
<td>Khedr et al. (2014)</td>
<td>7</td>
<td>R-AN and BP-AN</td>
<td>21.7 (mean)</td>
<td>3.4 years (mean)</td>
<td>tDCS</td>
<td>3 patients improved in all rating scales after treatment and maintained improvement at 1-month follow-up. 2 patients had improved at the end of treatment but returned to the baseline after 1 month. 1 patient improved only on the BDI scale. 1 patient showed no improvement.</td>
</tr>
</tbody>
</table>

Note: BDI = Beck Depression Inventory; EAT = Eating Attitude Test; ED = Eating Disorder; EDE-Q = Eating Disorder Examination Questionnaire; EDI = Eating Disorder Inventory; BP-AN = Binge/Purge-AN; DLPFC = Dorsolateral Prefrontal Cortex; R-AN = Restricting-AN; MDD = Major Depressive Disorder; MT = Motor Threshold; rTMS = Repetitive Transcranial Magnetic Stimulation; tDCS = transcranial Direct Current Stimulation.
duration, thus no evidence-based practices likely to produce clear-cut, long-term benefits have as yet been established for treating SE-AN or AN generally. Although isolated findings and generally weak evidence describing positive effects on weight in placebo-controlled randomized trials have been described in some investigations of antidepressants (amitryptiline, fluoxetine) (Halmi et al., 1986; Kaye et al., 2001), antipsychotic medications (pimozide, olanzapine) (Vandereycken & Pierloot, 1982; Bissada et al., 2008; Attia et al., 2011), lithium (Gross et al., 1981), zinc supplementation (Birmingham et al., 1994), cyproheptadine (Halmi et al., 1986), and a cannabinoid agonist (dronabinol) (Andries et al., 2014), these findings were not usually replicated or supported by systematic reviews or meta-analyses (Claudino et al., 2006; Kishi et al., 2012; Lebow et al., 2013). In addition, limited evidence supports the use of antipsychotic medication for obsessive thinking in AN (Mondraty et al., 2005; Bissada et al., 2008), and of hormones to improve BMD (Grinspoon et al., 2002; Miller et al., 2011; Misra et al., 2011), the last an important aspect for those with SE-AN and increased risk for fractures. Notably, only one pharmacological trial focused specifically on individuals with SE-AN, and on modulation of eating behavior (dronabinol), a medication that may be worth further study (Stephen et al., 2006).

If one considers the evidence base, pharmacotherapy should not be recommended for the treatment of AN, and guidelines not only do not support its use as monotherapy (NICE 2004; APA, 2006; Hay et al., 2014) but also emphasize its potentially harmful effects, including possible increased medical risk, an issue that may be of particular concern for those with SE-AN and debilitated health (Hay et al., 2014). However, there is research to inform on its common use in clinical practice among adolescent and adult samples, especially antidepressants and atypical antipsychotic medications, usually used adjunctively to refeeding programs and aiming to improve mood, and reduce anxiety, agitation, and obsessional thinking (Powers et al., 2012; Moore et al., 2013). In the face of the serious psychological and medical status among those suffering with SE-AN, with reduced life expectancy, fragile nutritional and physical condition, and poor global functioning and quality of life, pharmacotherapy may be a justifiable adjunct to other treatments, with maximum vigilance to medication side-effects and any potential worsening effects on health. Clinical experience and close monitoring should be used to balance observable positive (helpful) with negative (harmful) effects of medication treatments.

The question of what makes AN so resistant to so many pharmacological interventions is intriguing and deserves exploration. It is expected that a better understanding of the neural bases for the behavioral and psychological features that shape the development or maintenance of the disorder will lead to the identification of more adequate targets for biological interventions, including pharmacotherapy. This idea underlies...
the invasive and non-invasive neuromodulation strategies currently under investigation and offered in the research context. So far, data in AN demonstrate potential for symptom improvement, including weight gain, following both rTMS and DBS. One interesting approach may consider the potential for neuromodulation, particularly the non-invasive methods, to be used as an adjunctive treatment, since neuroplastic changes may “boost” pharmacotherapy and psychotherapy effects. Advances in this field might inform whether neuromodulation will become an option for those who do not respond to or cannot tolerate standard treatments.

The ED field continues to improve treatments, but evaluating long-term outcomes and identifying treatments for the subset of patients with severe and enduring symptoms represents critical future directions. Continued efforts to incorporate novel technologies into treatments will hopefully offer the opportunity to address aspects of AN that have not been previously targeted as outcomes in treatment trials, such as medical and nutritional improvements aside from weight gain, and quality of life improvement. Novel study approaches for novel treatments may make personalized treatment tailored to patients’ particular characteristics and stage of illness a possibility.

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Managing Severe and Enduring Anorexia Nervosa

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A Life Wasted
The Patient Perspective

June Alexander

I regained my self from anorexia nervosa (AN) in 2006, 44 years after developing the illness. My story adds to the pile of evidence that recovery can be achieved at any age. What is “recovery,” anyway? I prefer the word “freedom.” To place my experience with AN in context, I present decade-by-decade snapshots. First, an aside: this chapter title doesn’t sit well with me. I don’t consider my life “wasted.” Not now.

1950–1960

I was born between Christmas and New Year, 1950. My parents, who ran a family dairy farm, lived with my paternal grandparents at the head of a beautiful, fertile river valley in Victoria, Australia. The property was adjacent to what would become the Mitchell River National Park. It would be my playground. There I would “escape,” to wander through the bush, among the gum trees, tea-tree scrub and ferns, up and down gullies, across creeks and moss-covered rocks, feeling at home with kangaroos, wallabies, wombats, lyrebirds. Closer to the river, I would see goannas, bearded dragons and salamanders, and watch out for snakes and, when lucky, see platypus somersaulting playfully beside the riverbank. This was my soul-place and the place from which I would draw strength in the decades to follow.

At the time I was born, my parents did not own a car or a tractor—my dad was using draught horses to cultivate his fields—but my grandpa had a Ford car, and this provided transport to the nearest hospital in Bairnsdale, 20 miles away, for my birth. My mother had been to the doctor the day before and was told to return in three weeks for another checkup. She went home. But I was born six weeks prematurely, the very next day.

During this period the family home was not connected to electricity and had no running hot water. Communication with life outside the valley was provided by a large wireless that sat on the kitchen floor, a phone that was fixed to the passage wall, and weekly newspapers. I had one sibling, a sister, 30 months older. All photographs taken during this period show my
sister in pink, with her long hair in ringlets, and me in blue, with snowy hair, cropped short.

My mother called me Tim when I was good and Toby when I was bad. I was happy as a tomboy. I loved helping Dad on the farm and did chores from the age of five, such as filling the kerosene bottles for the lamps at night, feeding the chooks, collecting the hen eggs, and feeding the calves at the dairy. I glowed with pride when Dad told an uncle that I was a left-hander at writing, but his “right-hand man” on the farm.

My greatest interest inside the home was reading and writing. Newspapers fascinated me. I sat on the kitchen floor as a three-year-old, turning the pages, gazing at column after column of black print and thinking: “When I grow up, I am going to read every word.” The written word somehow seemed safe. It seemed precious. I couldn’t understand why my parents didn’t read every page more closely. I don’t recall them ever reading to me, and I never saw either of them reading a book, but nonetheless I had this passion for reading and writing, along with an affinity for nature.

Two big events occurred at age five. My formal education began in a one-room, 20-pupil state school that was surrounded by crops and cow-studded fields. To get there I pedaled a bike 2.5 miles.

The same year, my grandparents moved into a house in Bairnsdale. Grandma died when I was 10. I missed her and spoke with her in my prayers, whispering under the blankets each night; long after the candle was snuffed out. When Grandma and Grandpa lived on the farm, I sometimes awoke next morning in their bed, feeling safe and snug with a grandparent either side. My parents would place me there in the middle of the night when my bed was needed for visitors. Before getting up, Grandma would let me lie close to her for a while, and would gently scratch my back; she would let me help clip up her tight-fitting corsets, and brush her beautiful, long silvery-white hair that she wore pinned into a neat bun during the day. She also taught me to knit and crochet. The only intimacy I recall as a child was this time with my grandma.

When Grandma died she left a small Vegemite jar with a hand-written scrap piece of paper taped on top, stating: “This is June’s.” The jar contained pennies, halfpennies, threepences, and sixpences. I treasured that little jar, for its message more than its contents. In years to come, those three words, which I still have, penned in my grandma’s hand, would hold deep meaning for me, and give me strength.

Meanwhile my love of words continued. At age eight, I wanted to be an author. Books, at home and at school, whether age appropriate or not, fired my imagination. At age nine, I won my first prize, a pen, in a story-writing competition. Until this time, I had only one teacher, who took all six grades in the school. Then a new teacher came. He was a cousin, just out of teachers’ college, and he boarded in our home. My sister and I found him “creepy.”
My sister and I shared a bedroom, which had a fireplace and a tall, sash window. Before getting into bed, my sister had routines, one of which was to look in the wardrobe, under our beds, and up the fireplace chimney. She refused to tell me what she was looking for. Some nights we would lie in bed and she would insist: “There is a light outside the window.” She would go on and on, and I would get out of bed and assure her there was no light, but she would insist to the point I also would get upset and worried, and call our parents in. I would try to be helpful, to compensate for the disturbances created by my sister’s behavior.

1960–1970

Helping Dad on the farm was one way to avoid being inside with my mother and sister, who seemed to argue a lot, but also needed each other in a way I didn’t understand. They called me “stubborn” and “pig-headed” for preferring to help Dad, or wander alone in the bush, rather than go visiting with them or play at a friend’s house. When I was ten, my grandma died.

Age 11

In sixth grade, the final year of primary school, four major events occurred.

- Two weeks after my 11th birthday, in the summer holidays of 1962, I got my first period. I had watched bulls mating with cows plenty of times, but was completely unaware of human habits. When my mother noticed blood on my sheets one morning, she called me into her bedroom, and gave a brief description. Feeling a great need to escape the house, I pulled on my gumboots and headed to the dairy to help Dad clean up after the milking. As I walked down the track, kicking pebbles with my boots, I stopped. My mother’s words hit me. I felt my world had fallen in. For a week out of every month I would have that bleeding; every month, because I was a girl. I didn’t want to be a girl; I wanted to be Tim. I felt mortified and hoped Dad would not notice there was something different about me. Several weeks later, the new school year started.

- I was the only girl in the school with breasts. When I ran, they bounced up and down and hurt. If I held them they didn’t hurt, but this was embarrassing to do when playing with the boys or within sight of my schoolteacher cousin. The following month came the announcement that the school doctor, who did health checks each three or four years, would come in June. We were given consent forms to take home. I didn’t want to see the doctor but Mum said: “Don’t be silly. You have nothing to worry about, Tim. It will be over in a flash, you’ll see.” Her words provided no comfort. We children would have to
undress to our underwear in a classroom that had large, multi-paned windows, and no curtains. I feared undressing in proximity of my cousin. My sister was no help, saying: “All the other girls will be undressing; you won’t be the only one.” But I would be the only one with breasts. This was definitely something I couldn’t talk to Dad about. The doctor’s visit was only three months away and there didn’t seem any way out. Then one afternoon, while sitting on the grassy school grounds during playtime, the tension suddenly eased; it was like a “ping” occurred in my brain. What I didn’t know, was that AN was developing. That same afternoon, when classes resumed, a health lesson provided encouragement. The lesson was about food values and burning energy, and a new word: calorie. A day earlier I would have dismissed the word immediately but today my mind latched on with magnetic force. More than 50 years later I can visualize that page in my health book, the two columns of bullet points, one listing the calorie content of several foods, including apples and bread, and the other listing the number of calories absorbed in 30 minutes of walking, swimming, running, and bike riding. I memorized it all, and from that day began to eat less and exercise more. The school doctor came and went, but I remained too afraid to eat. My periods ceased. My ankles swelled, sores broke out on my fingers, I would not sit still. My parents despaired (“What will people think?”).

- The family homestead was connected to electricity, and appliances were installed, including a television set. I was incapable of being excited.
- A Christmas gift of a small diary, however, did excite. We bonded immediately, and so began a relationship that continues to this day.

**Age 12**

Secondary education involved catching a bus to Bairnsdale, where I became one of more than 400 students. My mother, in a bid to make me eat, delayed purchasing my new school dress. This tactic failed, and the dresses sold out. I was one of only five girls who began the year “out of uniform.” Embarrassment, shame, and stigma cut deep.

By now my parents were taking me to doctors, including twice to a psychiatrist who told them I didn’t want to grow up; and that I wanted to be a boy.

I was fast losing interest in life when a small miracle occurred. My mother had been baking fairy cakes in her small wood oven on a hot day for my sister’s birthday. She was in a hurry and when she took the tray of 12 cakes out of the oven, they sank. She was about to cry when I managed to say, after a year of severely restricted eating: “Don’t worry Mum, I will eat them.” And I did. I ate all 12 cakes. I made Mum happy. Suddenly I could eat. I gained 10kg quickly and didn’t see the psychiatrist anymore.
I became more outgoing at school, and kids were saying “June has come out of her shell.”

Age 13–14

My sister moved to Melbourne to study, and for two years happiness reigned. Life revolved around helping my parents on the farm, developing friendships, and enjoying school. At age 14, for instance, my weight stayed steady all year; I won a scholarship, was dux of Year Nine, and was first across the line in the annual school cross-country race. But all was not well.

Age 15–16

My periods had not resumed and my mother, feeling concerned, took me to a doctor who prescribed the Pill. The first attempt of three months failed to resume my menstruation, so the doctor prescribed the medication for another six months. This time, it worked, I became buxom and gained 7kg in 14 weeks. Everyone thought I was “normal.”

A young man, George, won my heart at a local country-dance. He was from a large farming family that my instincts suggested was solid in structure, secure, and safe. My parents approved of his family, but I had less time to help on the home farm. If caught reading a book on the verandah, Mum would say: “Get out and help your father, you know how tired he is.” I felt guilty if sitting down, guilty if I were happy. I felt a pull between wanting to be Tim and being a farmer with my dad, being with George, and pursuing a formal education. It didn’t help that every time I had my hair cut to a short style, my mother said: “We’ve got our Tim back”.

For the first time, my diary mentioned the word: “depression.”

Age 17–18

Anxiety was escalating, especially at exam time, and I increasingly resorted to calorie counting as a way of coping. Bingeing and restricting behavior intensified during a year as an American Field Student in Midwest USA. Mood swings became more difficult to hide. On returning to Australia, I ignored teachers’ encouragement to attend university, and took what seemed the less demanding option as a cub reporter with my hometown newspaper. This decision also enabled me to live in the same district as George.

Age 19–20

Very soon, George proposed and we became engaged. I loved George but every decision I made was affected by how I was coping or not coping with calorie counting. I wondered if more time to “be sure” would be helpful but when I tried to discuss this with Mum, she said: “Why do you
have to be so complicated, why can’t you be like other girls in the district and just settle down?” I went for more walks in the bush and along the river, trying to connect with my self and work out who I was.

Marry George. Don’t marry George. Marry George; get away from parents. Marry George. Stop this uncertainty. I married George. But AN came too. I fainted on the morning of my wedding. Fainted regularly. Ten weeks after the wedding, I binged on ten scones one morning before driving to work in the newspaper office. Lacking concentration, I drove under a loaded log truck and sustained cervical spine injuries. George always said: “You weren’t the same after that accident.”

Also at this time, my sister, who had married several years earlier, gave birth to a son. His name? Tim.

Age 21–25

My first pregnancy was not planned. I was in the third year of my journalism cadetship, and babies were off my radar. Once I became pregnant, however, I proceeded to give birth to four children within four years. Having babies became a way of creating a milestone: each pregnancy gave nine months to get myself “in order,” to stop bingeing, eat normally, to be free of this torment.

I can have xxx calories per day until Bubsie comes, then xxx, only increasing if weight falls below xxx, and decreasing if above xxx six weeks after Bubsie’s birth.

Author’s diary, 1976

But within a week of each birth, the binge-starve cycle became worse than before. Five months into the third pregnancy, acute appendicitis required an emergency operation; early in the fourth pregnancy, I almost lost the baby. My body lacked iron, among other things. The gynecologist said he was not worried about the baby being small, but about it starving. He didn’t ask about nutrition and didn’t know about my rollercoaster eating patterns or dark moods. Four weeks prior to my due date, the doctor said: “What a scungy kid you’ve got in there.” His words stung but, because he was the only doctor who performed the tubal ligation operation, I had to remain his patient. At some level, I knew I could not go on having babies. I was the major breadwinner, continuing to maintain employment at a time when many frowned upon working mothers, and the only way to stop this pattern of having babies was to have a tubal ligation before returning home with Baby Number Four. However, the tubal ligation would also prevent my use of pregnancy as a lever to fight my tormentor and this worried me.

Now that the baby option was eliminated, descent into chronic depression and anxiety was swift. About this time, a cousin revealed that the reason my mother had no more children after me, was because: “You
were a difficult birth.” Thinking this might explain a lot, I broached the
topic, but Mum flew in anger and wanted to know who had told me
such a thing. Her stock answers to any question relating to the past were:
“That happened a long time ago” and “We don’t talk about those things.”

Age 26–28

I was working full time, with four children under six, undertaking a long-
distance journalism studies course, and supporting my husband while
he pursued job satisfaction. Still my mind twirled, constantly with food,
food, food. I wrote in my diary that I was losing the plot, fearing madness,
that I would be locked up, lose my children. Or perhaps I was just plain
weak. Outwardly, I presented as a wife, mother, journalist, sister, and
daughter, as someone who made time to bake cakes for the school fair,
who had everything one could possibly want, but the diary revealed a
different story: daily lists and pledges reflecting a desperate bid to gain
peace and clarity in my mind. Getting through the day required:

- weighing this number of kgs.
- running this number of kms.
- eating no more than this number of calories.
- . . . and doing this, this, and this.

At age 28, deep love for my four young children drove me to share
what were, by now, suicidal thoughts and actions with a doctor for
the first time. Four years of misdiagnosis followed: the first doctor said
my brain had a gap or deficiency, which affected large brain messages
to do with mood, memory, self-esteem, and so on. Possibly, a lack of
oxygen to my brain had occurred in the few hours before I was born.
He wrote a prescription for pills and said: “You will be a new person.”
No, I felt worse. He referred me to a clinical psychologist who probed
a little further, diagnosed chronic hypoglycemia, and provided a special
diet. The psychologist prescribed vitamins and minerals at ten times the
normal dosage. He concluded that I binged because I was deprived and
felt unloved, that the basic problem was my marriage, and suggested I
needed more hugs. I tried to believe the hypoglycemia diet was helping but
was fooling the psychologist and myself. All the while, the symptoms were
getting more severe. Repetitive sounds, like a child tapping a teaspoon on
the table while waiting for dinner, drove me crazy; my head felt as fragile
as an egg without a shell.

Age 30–40

The eating disorder dominated this decade. This period was painful. The
eating disorder had consumed almost all of my true self. The thoughts and
behavior recorded in my diaries belonged to AN, not me.
Self-harm provided the only release. Things got worse after my sister phoned, in a distressed state, blurring out that the reason she looked under the beds in our childhood was because a cousin had entered the bedroom more than once, engaging in acts of sexual molestation. She was eight years old at the time. I was five. Our parents still welcomed that cousin into their home. My sister insisted we not tell them. Pieces of my life jigsaw were starting to fall into place but I could not discuss their impact with the people affected most...my family.

At age 32, a new country GP listened to my plea for help, and said “I know of one man who can help you.” The appointment to see Professor Graham Burrows, in Melbourne, would take seven months. My husband and I moved our family to the city, for easier access to treatment, and for better employment opportunities. As soon as I met Professor Burrows I thought “this man can help me” for he saw me beyond the illness. The diagnosis was AN, chronic anxiety, and depression. Despite my chance of recovery being listed only as fair, due to the illness entrenching itself in my brain during the previous 20 years, I felt hopeful. However, things would get worse before they got better. Medication was prescribed immediately, and soon a new crisis developed. It was like the eating disorder became outward as well as inward. My morals and values went to the wind. My psychiatrist said I was having a crisis. Disintegration of self was complete.

At 36, by now working for a major metropolitan newspaper, a male colleague made sexual advances in the office lift. I immediately clung to an unshakeable belief that he represented my key to inner peace. I entered a severe phase of restrictive eating and excessive exercise. Within ten weeks, my 15-year marriage was over. I gathered my four children, age 8 to 12, around me, and explained that my choice was to leave their dad and live, or to stay and die. The illness had reduced me to this.

I packed, and left. The man in the lift disappeared. I was lost in a state of nothingness.

My mind began exploding more regularly with torment. I would self-harm, hitting my head on the wall or floor until blackness swept in, providing momentary relief. Physical pain was preferable to the perpetual mental and emotional anguish. When this happened in the newspaper office, I had my first admission as an inpatient to the Melbourne Clinic.

[My husband steadfastly, to this day, blames the psychiatrist for the break-up of our marriage; my view is that the psychiatrist saved my life, partly by numbing my brain with drugs; I lost my marriage but gained my life. That was the price.]

The turning point came one weekend when my entire family, except me, was invited to my father-in-law’s 90th birthday. Home alone, I descended into my customary black hole of aching emptiness, but this time the rejection pain was particularly acute; so sharp it sparked a moment of enlightenment. I saw in my soul a tiny thread of self, and
knew I must cling to this thread for this was true me. It gave insight that I had been born, and had a right to life. I had to rebuild an identity that was authentic, that was me.

I began in a practical way the next day, arranging to resume my birth name: June Alexander.

Besides my psychiatrist, I spent many tearful hours exploring guilt and shame with my minister of religion, who assured me: “Every reason for having a baby is a good reason,” and “God is in favor of new starts.” It didn’t matter how many.

Slowly, the U-turn was achieved. The desire to recover took hold. At the age of 38, I wrote:

> For years I have been searching, seeking my identity, my purpose, my meaning, in life. Years. And I’ve concluded that I am a prisoner to myself. And if I don’t set myself free, if I don’t take a stand, I will live the rest of my life feeling frustrated, and unfulfilled; I will not know the joy of inner peace, or the achievements I can enjoy if my energies are set free in a positive way.

> I can see that, for many years—since I fell prey to anorexia nervosa—much of my creative energy has been wasted in a negative way, for I have turned it on myself, my own private obsession with food has robbed me of my true self.

> I have had some hard lessons. I know I can live with myself only if I accept that my mistakes, my bad experiences, can be the catalyst, the seed, for new beginnings and fulfillment.

> I find great difficulty in understanding myself, my behavior, but I must try to understand myself, my fears, my needs, if I am to correct myself and live out the rest of my life free from the nasty inhibitions that have plagued my inner self for so long.

> Author’s diary, 1989

Age 40–50

The AN thoughts continued to plague relentlessly:

> I don’t know if a thought is of the true me, or belongs to the eating disorder, or is influenced by prescription drugs.

> Author’s diary, 1992

Finding a way out of the dark forest of the eating disorder was difficult, but slowly another thread of self was found, and another, and another. By weaving them together, I was forming the foundation of “me.”

A dietician, aware of latest research in the eating disorder field, in family-based treatment, and also in mindfulness, managed to gain my trust. I began to see that I had to learn to trust myself, and not the eating
Managing Severe and Enduring Anorexia Nervosa

disorder, before I could have a healthy relationship, with others or myself. She explained that the eating disorder thoughts were not of the true me. This insight was a great comfort and relief. Sorting the illness thoughts from true thoughts was a big job, and it followed that I then needed to catch the illness thoughts and defuse them before they took off. This task, commenced at age 47, of getting in touch with my feelings, and taking care of them, would take eight years to master and indeed is ongoing. At the same time I would succeed in my long-held challenge of eating three meals and three snacks a day. This sounds an easy feat but after 30 years of food ruling my life, it was remarkable. My diary became a place for recording progress and practicing self-awareness.

Two operations also provided important recovery steps: one was a hysterectomy. The other was the insertion of a 6cm titanium rod, buttressed each end from C4 to T1, in my cervical spine. Four discs and three vertebrae were taken out. Twenty-seven years after colliding with the log truck, technological advances had enabled this operation. My neurosurgeon, besides caring about my spine, cared about me. He arranged for a psychiatric colleague to visit my bedside. I was told that an “internal saboteur” was causing constant chaos in both my inner and outer life. To be free, I had to identify and eliminate it. This fresh insight helped me to externalize the AN and view it as separate from self. As a step toward building self-belief, the neurosurgeon and psychiatrist insisted I repeat the mantra “I deserve to be treated with respect,” over and over until it worked like an autocue in my brain.

Age 50–60

Pieces of my life jigsaw continued to appear. There is hardly a right time to disclose long-held secrets, but certain times, such as funerals, are worse than others. In my family, the sudden death of a brother-in-law led to the release of a secret that had nothing to do with him but related to the childhood abuse that had occurred in the family home, 45 years before.

The morning after the funeral, in the farmhouse kitchen, the secret spilled out. The revelation that my parents knew about the abuse, and had ignored it, and continued to welcome the abuser into their home rocked and shocked me to my core. After that momentary revelation, everything clammed up again. Discussion refused (“What makes you think you are so special, it happens to other people too”). No action taken. No chance for wounds to be cleansed or tended to, no family healing possible. I required months of intensive counseling to regain recovery momentum.

My illness had been part of me for so long, the task of disconnecting from its thoughts and behaviors, and reconnecting with my true self, required confronting and working through many layers of secrets. I also had to overcome a fear of being alone. Since leaving George, I had been attracted to relationships where the male’s personality aligned mostly with
AN’s initially charismatic but subsequently dominating nature. Exciting, but dangerous. Chaos was a bully in my brain. Feelings of rejection, worthlessness, and alienation were familiar and “normal”; feeling safe, secure, and stable was frightening. Oh, so many challenges.

Physically, diagnosis of the autoimmune condition, Hashimoto’s Disease, marked another step in the rebuilding of Self. Medication (ongoing) for this condition has helped considerably in advancing general feelings of wellness.

**Fifty-one Percent Me**

My daughter’s wedding and my mother’s 80th birthday, became of great significance in late 2005, for they required me to push emotional boundaries and confront fears. With therapists, family, and friends guiding the way, I focused on applying mindfulness and imagery strategies to cope with and embrace these two emotionally-charged family celebrations, and received a priceless reward:

As dusk gave way to night, I sat on my wooden veranda and watched the geese gather on my dam . . . Gazing upwards, to the full moon and Milky Way in the gloriously clear star-studded southern sky, I suddenly felt an intense moment of great elation. YES! The little girl inside me had escaped her eating disorder prison!

*Author’s diary, 2006*

I had crossed the line. By attending to emotions instead of numbing them with food binges and starvation, I had succeeded in connecting with “me” more than the eating disorder. This moment of achieving 51 percent integration with self was akin to the “ping” moment in the schoolyard 44 years earlier. One heralded the start of the illness, the other, the end. Now that I had more say than the AN, progress accelerated in the coming months. Thoughts turned to a long-held dream of writing my story. I felt driven to expose the AN monster in words, feeling certain such exposure was necessary to complete its extermination. The illness had thrived in the dark, on secrets, and by isolating my self from body and from people I loved. My book would put it in the light.

First, there was one more hurdle. I discussed with my psychiatrist a desire to be totally me while writing my story, and negotiated to ease off 30 years of antidepressant medication; this process would take seven months. He was doubtful, but weeks passed. I coped.

Serendipitously, in the same week I took the final 10mg of medication, my first grandchild was born. This child’s birth in September 2006 has become my marker for freedom from depression. Today, I have five grandchildren and they, together with my children and their partners, provide a powerful tonic that doctors cannot prescribe: Love.
In 2007, I resigned from a 38-year career in newspaper journalism, to focus on the dream I had as an eight-year-old: to be an author and tell my story. Throughout the decades of treatment for AN and comorbidities, the doctors and specialists unanimously had said: “Keep writing,” “Continue working at the newspaper.” Even when an inpatient in the eating disorder clinic, I went to the office during the day. Employment served as a medicine; it helped to save my sanity; often it was my only evidence that a tiny part of me was worthwhile and okay. Now, I was ready to depart journalism, to reveal the story of my private hell and show the eating disorder I was not afraid.

2010 Onwards

Tentatively, driven by an urge to learn more about the illness that had profoundly affected my life and that of my loved ones, I began to attend eating disorder conferences. There I was at the first such event, a sufferer, among all these highly professional and respected people. I felt nervous and out of place, until the researchers stood behind the lectern to describe their latest findings, and then I sat entranced, on the edge of my seat, wanting to shout in elation: “You are describing my life, you are helping me understand me.” Their words illuminated my mind. They helped me accept that I was an okay person. I began to feel I belonged. I had had an illness that had robbed me of self-belief, that was all.

Sadly, efforts to reunite with my family of origin failed. My parents and sister had labeled me the “Only one with a problem in the family” and, for many years, I believed them.

Now, however, I could see that an eating disorder affected every member of the family. I wanted to show my parents and sister that the little girl they knew and loved all those years ago had been present all the time, suppressed by the illness. I continued to seek family unity and acceptance. But perhaps too much time had passed, for they had made a life that did not include me.

My children’s dad had accompanied me to each of my parent’s funerals, in 2009 and 2010. As we departed the church from the second funeral, he said: “Now you are free. Our children and our grandchildren are your family. Focus on them.”

His words were true, and healing has continued in unexpected ways. My father’s will had revealed gifting of the family farm to my nephew, Tim, years before, and the homestead was left to my sister. I was not invited to visit my childhood home to choose so much as a keepsake. In a bittersweet way this formal, legal notification enhanced my healing through reinforcing the nurturing words of my carers and treatment team: I hadn’t imagined the rejection after all. It was real. The painful decades of feeling alienated were over and I was free to move on.
Family of Origin, Family of Choice

It is tough, awfully tough, escaping the AN prison with your life but without your childhood family. I cope by counting blessings. Interests developed in childhood have helped me get through: a passion for writing, a love of nature, and the love of my grandma who wrote: “This is June’s.” Now, I understand her message: developing self-acceptance, rather than trying to gain acceptance from others, is what matters most.

I’m sure my parents loved me, but they didn’t know how to distinguish “me” from the illness or how to help me. I had to change, to live, but they became comfortable in a groove that had no room for me. I owe my life to a support network that includes my children and their families, their dad, friends, psychiatrist, therapists, doctors, neurosurgeon, minister of religion, and faith in God. Although I lost my family of origin and my marriage, I have gained another family in recovery, a family comprising people from all walks of life in the eating disorder field. This “family of choice” nurtures my fledgling self-belief. Respecting helps the patient to practise self-compassion, be hopeful, and push fear away.

Writing has enabled me to re-story hurtful, traumatic experiences and embrace the current moment. The anxiety that preceded my development of AN remains part of who I am. The difference today is that I have skills and support to manage it. The passion for writing that helped me to survive privately has become a sword in fighting eating disorders globally, through disseminating evidence-based research and being a voice for others.

Love, adequate nourishment, walks by the seashore and in the bush, connecting socially with others, and continually developing a sense of belonging and fun, is my maintenance program. I’ll never know if I am the person I would have been if I had not developed AN at age 11. What I do know is that I am free.

My life is not wasted. My life has purpose: as a mother, grandmother, writer, and advocate. Most precious of all, I am me.
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