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Clinical and scientific review of severe and enduring anorexia nervosa in intensive care settings: introducing an innovative treatment paradigm

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Abstract

Background Anorexia nervosa is a serious and potentially lethal psychiatric disorder. Furthermore, there is significant evidence that some individuals develop a very long-standing form of the illness that requires a variety of different treatment interventions over time.

Objective The primary goal of this paper was to provide a review of treatment strategies for severe and enduring anorexia nervosa (SE-AN) with the particular focus on treatments involving hospital care. Additionally, we wish to highlight a contemporary approach to such care and provide qualitative reactions to this model from both staff and patients.

Methods A selective and strategic review of the treatment literature for SE-AN was conducted for the current paper. Emphasis was placed on clinical or scientific papers related to hospital-based care. Additionally, staff who work on a specific inpatient eating disorder unit with a substantial treatment program for SE-AN, along with a number of SE-AN patients were surveyed regarding their experiences working on, or receiving treatment on the unit. Importantly, the staff of this unit created a specific treatment protocol for individuals receiving hospital care. The results of the highlight both advantages and challenges of a hospital-based protocol oriented toward emphasizing quality of life, medical stability, and a health-promoting meal plan.

Discussion While there is general inconsistency with the type of treatment that is best suited to individuals with SE-AN, this is particularly true for higher levels of care that rely on inpatient hospital units or residential treatment settings. This is a highly significant clinical topic in need of further clinical and scientific examination.

Plain English summary

Anorexia nervosa is a serious illness which often persists for decades. Treatments for persistent anorexia nervosa are not well defined and there is considerable debate in the field about appropriate types of treatment strategies for these individuals. Such clinical uncertainty is particularly noteworthy in terms of the most appropriate types of care

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for these patients when they are hospitalized, which happens relatively frequently. Greater efforts are needed to develop inpatient programs for SE-AN that take into consideration their unique clinical needs.

Keywords Anorexia nervosa, Disordered eating, Eating disorders, Severe and enduring anorexia nervosa, Higher levels of care

Background

Anorexia Nervosa (AN) is a serious and potentially lethal psychiatric disorder that is most typically seen in girls and young women, with a lifetime prevalence of 2–4% [1, 2]. While AN is rare in some countries (e.g., Africa and Latin America) it is most prevalent in Europe, North America, and Australasia. AN is considered one of the most lethal psychiatric disorders with a crude mortality rate of 5% per decade and a standardized mortality ratio of around 6 [2, 3].

Prospective longitudinal studies have consistently identified a subset of AN patients who have long-standing eating disorders, characterized by minimal improvement and significant impairment over decades (e.g. [4, 5]). However, there has been significant variability across studies in terms of rates of remission and recovery from AN. Eddy and colleagues [5], suggested that the longer the duration of follow up in such prospective longitudinal designs, the greater the rates of recovery. Steinhausen [6] reported that in studies with follow up to four years since index diagnosis, recovery was approximately 33%, while studies with follow-ups ranging from 4 to 10 years average 47% recovered, and studies longer than 10 years in duration revealed recovery rates over 70%. Robinson [7] examined the same literature and concluded that rates of recovery after 10 years seemed to be declining compared to follow-ups ranging from 4 to 10 years. Eddy et al., [5] suggest that studies beyond 20 years of follow-up are not only limited, but the findings are even more inconsistent. For example, Theander [8] reported outcomes over 33 years of follow-up with 76% achieving recovery. However, two other studies [9, 10] found that approximately 20 years after an initial hospitalization, around 50% of the sample of AN individuals was recovered. Ratnasuriya [11] reported that 20 years after hospitalization only 30% of the patients had a good outcome. Similarly, a study with a large sample of individuals treated for AN revealed that the longer the duration of the eating disorder, the lower the chance of recovery [12]. These findings are further supported by a recent systematic review on the treatment of eating disorders that showed that 40% of AN cases had partial or no remission of symptoms [13].

However, another important longitudinal study, by Eddy et al., [5] relied on a well-characterized and regularly assessed sample of both individuals with AN and bulimia nervosa (BN) over 22 years. In this study, the authors found that at the end of the first decade of illness, approximately 31% of the individuals with AN and 68% of the individuals with BN were recovered. Thus, BN appeared to be a much more remitting illness than AN. However, approximately two decades after the initial diagnosis, there was significant proportional change. At this point, approximately 63% of the individuals with AN and 68% of the individuals with BN had recovered. Approximately half of those with AN who had not recovered in the first decade did recover in the second decade. Interestingly, the recovery rate of BN did not change significantly over that decade. Thus, the study by Eddy and colleagues [5] suggests that recovery from AN may continue for decades after onset, but importantly, well over a third of the AN sample continued to have very significant AN moving into the third decade of the illness.

During the timeframe when many of these longitudinal studies were being conducted, clinicians were actively attempting to outline treatment strategies for long-term, persistent, and minimally remitting AN. Wonderlich and colleagues [14] summarized these clinical strategies, which were wide ranging and infrequently tested empirically. Overall, the collection of strategies reflected the informed experience of clinicians who had treated numerous patients with long-standing AN and served as a repository of clinical wisdom accrued largely during the 80s and 90s. Numerous recommendations and suggestions from these individuals still inform contemporary treatment strategies for SE-AN, such as establishing clear guidelines, the value of a team-oriented approach, the importance of meaningful treatment collaboration, inclusion of the patient's family, avoidance of aggressive change-oriented techniques, and the potential value of psychiatric rehabilitation models of intervention. Additionally, Williams and colleagues [15] described an integrated treatment program which included staff from hospital-based eating disorder program along with a community-based mental health rehabilitation team and demonstrated some degree of efficacy.

An important point in the treatment literature for long-standing AN was the randomized controlled trial conducted by Touyz and colleagues [16]. This study compared the efficacy of 30 outpatient sessions of an adapted form of cognitive behavioral therapy (CBT) to an adapted form of specialist supportive clinical management (SSCM). Both treatments had a modified primary focus on enhancing quality of life and promoting harm reduction, rather than weight gain and symptom reduction. Both treatments had excellent retention of participants, with attrition rates under 15%. Comparisons between

the two treatments revealed minimal differences in outcome. Furthermore, secondary analyses found a series of meaningful predictors of good response and revealed that quality of the therapeutic alliance was associated with positive responses, broadly [17]. Thus, this study offers support for the treatment of SE-AN and developing treatments that optimize patient engagement.

Several other empirical studies preliminarily have examined the impact of evidence-based, shorter-term treatments on SE-AN. Some of these studies suggested that treatments, such as CBT appear equally effective when delivered to individuals with AN versus individuals with SE-AN [18]. Similarly, two studies found that duration of illness was not a significant predictor of the outcome in structured treatment such as CBT and MANTRA [19, 20]. However, in another study, which relied on practice guideline-based treatments, there was a significant difference in outcome between early stage versus SE-AN patients. Specifically, the SE-AN patients were less likely to improve in areas of work and social adjustment than the early stage patients and the SE-AN patients were more likely to access intensive services following treatment [21]. There are an increasing number of empirical studies with SE-AN patients which could ultimately impact effective treatment deliveries, however at this point in time, the number of these studies remains relatively limited and frequently constrained by sample size issues. Thus, there is a significant need for additional strategies to be tested with individuals, displaying long-standing and serious forms of AN.

Wonderlich and colleagues [22] outline a number of innovative treatment strategies which have been tested, at least preliminarily, in individuals with long-standing SE-AN. They highlight that there are new behavioral strategies (e.g., exposure paradigms [23], habit-oriented interventions [24], cognitive remediation therapy [25]), along with novel pharmacologic interventions, (e.g., ketamine [26], and dronabinol [27]) which may have potential value in treating longer standing forms of AN. Additionally, there are brain stimulation interventions (e.g., rTMS [28], DBS [29]) which continue to be tested in individuals with SE-AN and show either reasonable tolerability or preliminary efficacy. Also, there are system-oriented strategies that are being looked at, such as stepped-care treatment models [30] and novel "self-admission" approaches [31] to inpatient care. Again, preliminary data suggests these strategies may have value.

However, despite these newer developments, we agree with the general idea that the lack of understanding of SE-AN and the associated dearth of treatments represent a serious deficit in the eating disorder field. Moreover, we believe that this dearth of empirically supported treatments for SE-AN patients is even more of an urgent situation for higher levels of care in hospital based and residential treatment settings as many of these patients repeatedly utilize a higher level of care. The primary aim of this paper is to highlight that empirically informed treatments for SE-AN patients are particularly limited in higher levels of care, such as inpatient units, partial hospitals, and residential treatment centers. Furthermore, we want to highlight the significance of this dilemma and the impact it has on SE-AN patients, and the clinical teams who attempt to treat them in these environments. In the next section, we will provide an overview of this situation and describe an innovative program, which has recently been developed based on clinical need and expertise, to provide quality care for SE-AN patients and also support the treatment teams who are attempting to provide the intervention.

Higher levels of care and SE-AN

Historically, there has been some debate about the most preferred treatment setting for patients with SE-AN. Some individuals clearly suggest that outpatient treatment is appropriate if medical stability is maintained [32]. However, Strober [33] advocates for inpatient hospitalization for SE-AN and suggests that comprehensive coordinated care is best provided in such a setting. Woodside [34] provides broad strategy for SE-AN patients when hospitalized, which happens relatively frequently. He notes that many SE-AN patients cannot realistically conceive of recovery but are interested in incremental improvements in their eating disorder. Others are interested in pursuing enhanced quality of life or improving their overall condition. He highlights the importance of collaborative goal setting that is realistic and tailored to each individual patient. There are no minimum standards for goals, virtually any change is promoted. Woodside does not provide high levels of detail about the operations of the program over the course of a hospital stay, but does conclude that there is an urgent need for increased dialogue about the issues regarding inpatient care and SE-AN.

Banford et al. [35] offer comments about the idea that eating disorder treatment programs, both outpatient and inpatient, often pursue treatment goals that are inconsistent with SE-AN patient motivation. Furthermore, many of these programs are oriented toward more acute cases of AN, often of younger ages than many of the SE-AN patients. Thus, the authors highlight the possible problems for SE-AN patients when they are in traditional eating disorder programs. They emphasize that when SE-AN patients are integrated into recovery focused partial hospital programs with younger, more acute patients, problems may emerge and they recommend that SE-AN patients are best treated in a separate program with individualized goals and interventions. They highlight that there are very few descriptions of SE-AN specific hospital

units in the eating disorder literature, but note that such patients are frequently admitted. They highlight that in an ideal SE-AN hospital unit, goals might include harm reduction, improved quality of life, achieving stabilization, reducing medical risk and decreasing crisis hospital dependency. Overall, they highlight an approach that is characterized by clinical flexibility, creativity, and adaptability for higher levels of care for SE-AN.

A recent systematic review of treatment interventions for SE-AN suggests that hospital-based care for SE-AN is not well understood and varies significantly across studies [36]. The evidence suggests that inpatient treatment for SE-AN may have a beneficial impact on eating disorder symptoms, but the evidence is unclear about whether or not such gains are maintained. Importantly, however, the five trials that are included in this review relied on a heterogenous collection of treatment strategies for these patients. Some programs were clearly oriented around cognitive behavioral therapy (CBT) while others were only partly based on CBT. Some programs included well defined nutrition plans, while others did not. Some programs relied on antidepressants while others did not. The length of the programs varied significantly, ranging from 3 to 5 months, which is a substantial variation. We would suggest that the clinical variability reported across the hospital-based programs in this review is representative of hospital programs broadly that treat individuals with SE-AN. In fact, this review provides support for the fundamental argument in the present paper, that there is a need for increased scientific and clinical attention to treatment protocols for SE-AN at higher levels of care.

Considerations for developing a treatment of SE-AN in higher levels of care

The Sanford Eating Disorders Unit in Fargo, North Dakota, is one of a declining number of hospital-based eating disorder programs with inpatient, partial hospital and intensive outpatient programming in the United States. In this program, we provide care annually to approximately 250 patients ranging in age from early adolescence throughout the life span. Additionally, we are one of a limited number of programs that openly accepts public insurance in the U.S. As such, we regularly provide care to individuals turned away from other treatment centers due to high medical complexity or insurance policies not covered by other programs. Typically, these individuals display SE-AN. Over time, the unit has attempted to develop a humane and effective approach to care for these individuals. In the hospital setting, we were forced to grapple with several ethical questions, such as whether we should provide care focused on full-weight restoration for a given SE-AN patient, when there is evidence to suggest that this approach has not worked well with the patient previously. Alternatively, should SE-AN patients be allowed to be admitted to the hospital without an active weight restoration based treatment plan, given the long-term risks of premature death in SE-AN? Thus, we sought to develop a treatment program that provides medical stabilization, promotes quality of life, and retains the possibility that one could, in fact, recover after years or decades of serious SE-AN [5].

In developing a standardized treatment approach for individuals with SE-AN, addressing the challenges associated with hospital-based care for individuals who vary significantly in terms of their desire or ability to restore weight was crucial. The heterogeneity of individuals with eating disorders is a significant issue in general but is even more significant in the shared space afforded by hospital treatment units. Thus, the typical hospital program for eating disorders must try to develop clinical programming to accommodate a wide variety of individuals. This may become particularly challenging when we consider that there is marked variability in the age of patients, the number of previous inpatient treatment episodes, and the total length of time they have been treated. In the case of AN, hospital programs must provide treatment programming for first-episode patients who are often adolescents and have significant family involvement, as well as long-standing patients with AN who may be significantly older, without family support.

Furthermore, there may be significant differences among SE-AN patients in terms of the degree to which the primary focus should be on weight-based recovery, or one that prioritizes a goal of maintaining medical stability and promoting quality of life. Importantly, these significant differences may, at times, be complicated for treatment teams in the hospital who are actively promoting weight-based recovery in one patient and maintaining medical stability and quality of life, or palliative or hospice care in another. Clearly, the complexity of patient experiences in a hospital environment with shared treatment programming and physical space limitations between patients is noteworthy, and a significant challenge for clinicians.

Another challenge for hospital-based programs is the impact of such diversity of patient characteristics on the distribution of valuable clinical resources. Hospital staff must repeatedly, and frequently, make decisions about who will be admitted when there is an opening for care. Should the opening be allocated to more acute, recent onset cases of AN in teenagers versus individuals with long-standing AN who have been hospitalized multiple times and not established significant weight restoration?

Furthermore, as we have noted previously, all of this clinical diversity and complexity in the hospital environment is increased because there is no well-defined, structured intervention for individuals with SE-AN in the hospital setting. As a result, there is often confusion

about whether treatment goals for such individuals should focus on weight-based recovery versus medical stabilization with enhancement of quality of life. There is also uncertainty about what treatment approaches may be beneficial to SE-AN patients. For example, in the hospital, what type of psychological intervention may be most beneficial for individuals with SE-AN? Should dietary interventions be modified for such individuals? What is the role of pharmacotherapy in the treatment of SE-AN?

Given these challenges, and the lack of any clear guidance in the literature, we created an active treatment program track for hospitalized individuals with SE-AN. Due to the need to capitalize on existing resources, the SE-AN track was developed entirely integrated within our traditional eating disorder inpatient program. This means that all patients, regardless of whether they are on the SE-AN track, take part in group therapy and eat in the dining room together. In an effort to reduce potential conflicts arising in treatment as a result of a mixed milieu, some adjustments to therapeutics and dining room rules were implemented. These are described in more detail below.

When developing the SE-AN track, our primary goal was to help our SE-AN patients improve their quality of life, primarily by reducing the duration and frequency of hospitalizations and creating a more personalized treatment approach. Second, we aimed to provide transparency between patients and clinical staff regarding the rationale and procedures for treating individuals with SE-AN. Third, we sought to establish a highly collaborative agreement early in treatment between a patient and clinical staff regarding structured goals to reduce future long-term hospitalizations. Fourth, we aim to actively engage with the patient regarding discharge planning at the start of treatment. The primary objectives of the program are to maintain gains established during the hospital stay, develop an outpatient treatment plan with explicit targets, and provide a clear understanding of the procedures utilized in the long-term treatment plan (which may include repeated short-term, return hospital visits).

A description of a SE-AN treatment program at a higher level of care

In deciding to change treatment outcomes for SE-AN patients in the hospital, it became crucial to re-examine the treatment approaches generally used on the unit, given that they were designed for traditional treatment targets (e.g., full weight restoration). Changes were made across almost all therapeutic modalities (e.g., psychotherapy, psychiatric interventions, and nutritional rehabilitation). For example, our goal was no longer primarily focusing on three to four pounds of weight restoration a week in the hospital. We wondered what this would mean for dietitians working with SE-AN patients or when determining the length of hospitalization. Furthermore, in a patient's psychotherapy, if quality of life is the outcome being measured, what should a therapist focus on in a session? Though specific quality of life interventions were not clear in the existing literature, what became clear to our team was the need to reduce the length and frequency of hospitalizations. We did not believe that a high-quality life could be achieved moving from hospital admission to hospital admission. However, SE-AN patients also often require significant time and support from providers at higher levels of care due to their high medical acuity arising from complications of their SE-AN. Thus, any quality of life focused treatment for individuals with SE-AN at higher levels of care must find a way to reduce time spent in the hospital by the patients, while also providing them significant ongoing support. This perspective (i.e., reducing frequency and length of hospitalizations while supporting the patients) became an overarching goal across all aspects of the SE-AN program. Below, we outline the fundamental procedures for the program.

Admission procedures and initiation of SE-AN treatment

As previously stated, one of the primary goals of the SE-AN program is to provide transparency and collaborative goal setting between patients and clinical staff. As such, discussing the SE-AN program goals should be started immediately, but not prescriptively. We believe the best approach for goal-setting is through collaborative formulation process among the treatment team and the patient, as this is one of the best ways to ensure adherence to treatment and improve clinical outcomes. Upon intake, patients are assessed as to whether they meet SE-AN criteria (e.g., duration of illness over seven years and multiple failed empirically supported treatment attempts) and their personal treatment goals are identified. Patients who meet these SE-AN criteria and express goals in line with improved quality of life and medical stability are informed of the SE-AN program. All new SE-AN patients are informed that their initial stay will be considered a brief evaluation stay of 2–4 weeks to achieve medical stability and assess readiness for the SE-AN program. During the first few days of the admission, patients meet with the provider to start an ongoing conversation about their therapeutic goals and receive psychoeducational materials about the SE-AN program. Patients are informed about the program's guidelines, including working towards specific goals, SE-AN-specific interventions, length of stay, and discharge planning, all of which are presented below. If, at the end of the evaluation stay, the patient and team decide that the SE-AN program is suitable for the patient, the "ongoing

admission" process is discussed. The details of the ongoing admission process will be described below. In short, this process ultimately allows the patient to return to the hospital on the SE-AN track for brief goal-oriented stabilization stays if they have adhered to their treatment plan for at least three months.

Treatment contract and goal setting

As noted by Woodside [34] collaborative goal setting that is realistic and tailored to each individual patient is crucial for treating individuals with SE-AN. While Woodside suggests that no goal is too small, we believe that at higher levels of care, goals must actively move the patient toward improved quality of life. Therefore, all patients with SE-AN in our program must set goals in three domains: quality of life improvement, ongoing medical stability, and maintaining a meal plan tailored to work with the patient's goals (e.g., weight maintenance or varying degrees of weight restoration). Patients are asked to work with their treatment team in each domain to establish 2–3 measurable objectives that will help them move their lives forward. For example, a quality of life goal might be "going to get coffee once a week with a friend," while an example of a goal to help a patient meet their meal plan requirements might be "establish appointments with an outpatient dietitian twice a month." The treatment team retains measurable objectives created collaboratively to measure future progress and decide the suitability of continuing specific SE-AN programming for future admissions.

Furthermore, individuals with SE-AN often carry comorbidities that may be treatment-interfering (e.g., substance use, obsessive-compulsive disorder, post-traumatic stress disorder). If the treatment team, or patient, determine a patient's comorbidities interfere with the SE-AN approach during the initial evaluation stay, additional goals must be set to address these ongoing issues either at the outpatient level of care or in a different treatment facility. For example, if a patient with SE-AN also experiences obsessive-compulsive behaviors, the patient and team must think through achievable goals (e.g., exposure and response prevention therapy or medication management) to reduce the impact on SE-AN treatment. These goals should be established with the treatment team and may range from traditional therapeutic interventions (e.g., exposure therapy or substance use treatment) to potentially more experimental approaches (e.g., repetitive transcranial magnetic stimulation [rTMS] or psychedelic-assisted psychotherapy) when indicated. The primary objectives regarding setting goals around comorbidities is to reduce treatment-interfering symptoms not directly related to the eating disorder outside the hospital and increase the likelihood an individual will be able to adhere to the treatment plan.

Another goal-related issue often pertains to step down and discharge planning. Following an inpatient admission on the SE-AN track, individuals may have the desire to step-down their level of care to a partial hospitalization program (PHP) or intensive outpatient program (IOP) to ensure a higher degree of aftercare compared to stepping down to outpatient therapy. As our primary goal is to improve quality of life outside of the hospital, our program has taken the stance that this is acceptable as long as there are specific, and clear goals that have been identified to work on while in the PHP or IOP. Additionally, we have occasionally utilized both PHP and IOP as the primary level of care for our SE-AN protocol; however, only for individuals who come to the hospital medically stable.

Specific interventions for SE-AN

Medical stability

One of the immediate priorities of a SE-AN approach at a higher level of care is addressing the patients' physical health and stabilizing any medical complications resulting from SE-AN. This includes addressing the various physical consequences of prolonged inadequate nutrition. Most crucially, medical experts should address issues such as cardiovascular complications, hypoglycemia, organ damage, electrolyte imbalances, and gastrointestinal distress that interferes with the ability to eat. While medication management of psychiatric comorbidities may also be necessary, the initial goal is to stabilize physical health so that there is a life remaining to improve.

Nutritional rehabilitation

An essential consideration for nutritional rehabilitation for individuals with SE-AN is the role of dietitians in the care team and developing simple, and achievable menu plans. While traditional goals, like improved diet variety, have been linked to sustained recovery following weight restoration treatments [37], the SE-AN program shifts away from what or how these patients eat, prioritizing only that they eat a sufficient amount. Thus, in collaboration with a dietitian, the SE-AN patient creates a meal plan based on foods they are already eating, described as "simple and doable." While the dietitian works to ensure the patient meets their macronutrient targets (within what is possible given what the patient is willing and able to eat),, there is initially less concern about various food or meal challenges. Over time, if patients successfully adhere to their meal plan, they may choose to increase variety or do meal exposures during future SE-AN admissions. As has been discussed among our team while developing this program, some of these recommendations may challenge the traditional treatment targets utilized by dietitians in treating eating disorders. However,

the concept of helping a patient find a meal plan to stabilize their weight and stop weight loss is a skill dietitians most likely already possess. Thus, this does not require extensive additional training. However, we encourage collaborative, and ongoing, discussions among the medical providers and the dietitians in determining various nutritional rehabilitation interventions, such as determining rate of increase in calories to stop weight loss while not destabilize the patient and potentially changes to the macronutrient breakdown of the diet to address medicals needs like treatment of edema. While many of the skills needed to treat SE-AN are already possessed by dietitians, specialized training for working with severely low-weighted, chronically-ill patients may want to be pursued by dietitians, or any of the team members, when it comes to how to best treat SE-AN patients nutritionally.

Another important consideration is how individuals with SE-AN utilize the dining room. Among providers, it has often been argued that the dining room is the most therapeutic intervention for individuals with eating disorders at a higher level of care. While this remains true for individuals with SE-AN, the dining room often serves a very different purpose. The primary function of the dining room is to support SE-AN patients who are trying a different eating model than what they have tried in previous treatments. For the treatment team, this might require changing the expectations in the dining room. For example, in our program, it is understood that patients with SE-AN may engage in some behaviors in the dining room that are often considered disordered. Rather than providing redirection for any eating disorder behavior (e.g., cutting food into small pieces, overuse of condiments), only behaviors that interfere with the patient's ability to consume their expected nutritional goals (e.g., delaying the start of their meal until the last 5 min so that they are not able to finish their meal) receive redirection. Discussions between SE-AN patients and staff should be supportive, calming, and reassuring. Calm, kind, and reassuring non-verbal messages are also encouraged. Ideally, SE-AN patients should be able to complete their meal in food, given that the patient and dietitian agreed the meal was simple and doable, and that these patients are given only the amount of nutrition needed for medical stabilization and to support their own weight goals, which often means halting weight loss and stabilizing and maintaining current weight. However if a patient does not finish their meal in food, they are expected to consume the missed nutrition immediately following the meal via a liquid supplement. Repeated refusal of planned foods or supplements suggests that the patient is not able to utilize and benefit from the SE-AN program at this time, and calls into question the utility of future admissions under the SE-AN track. The team and the patient would collaboratively discuss expectations for treatment adherence and how nonadherence may decrease the likelihood of the patient being allowed to continue treatment in the SE-AN track.

As previously noted, one of the challenges of creating a hospital-based treatment for SE-AN is the potential interaction of these patients with other patients pursuing different treatment goals. While this might not be an issue in some settings, the dining room can often create a space of conflict between individuals on a traditional restoration plan and those on the SE-AN program. To reduce interference with patients on weight restoration programs, patients on the SE-AN program eat at a designated table within the dining room. These simple modifications are essential in dealing with the heterogeneity of the eating disorder patient population.

Psychotherapeutic interventions

Psychotherapeutic strategies for patients with eating disorders at higher levels of care, in general, are extremely varied, making decisions about psychotherapy interventions for individuals with SE-AN difficult [38, 39]. Given that the goal of our SE-AN program is to promote quality of life and increase time outside of hospital units, we have shifted the programming towards values-oriented therapies [40] and skills-based distress tolerance interventions [41]. Acceptance and Commitment Therapy (ACT) techniques, like cognitive defusion and committed action, help patients deal with ruminative thinking, a hallmark of SE-AN, while pursuing valued goals following discharge from the hospital. Meanwhile, Dialectical Behavior Therapy (DBT) distress tolerance skills help SE-AN patients more effectively cope with the distress involved in changing eating disorder behaviors and resisting eating disorder urges, in order to approach valued personal goals, even when distressed. With these simple interventions, we hope to help patients increase their treatment motivation and adherence to the treatment plan. The hope is that this approach reduces the pressure on the patient and leads to greater hope and self-efficacy, as they take steps toward recovery in achievable ways, rather than having patients see recovery as an externally imposed goal that is also an insurmountable obstacle.

Additionally, conventional relapse prevention planning, consistent with Cognitive Behavioral Therapy (CBT), is also promoted to assist patients in adhering to clinical goals regarding relapse in the SE-AN program. An essential structural treatment issue is the need to strongly promote continued collaboration with the patient's outpatient providers following discharge from the hospital program. Such ongoing collaboration is necessary for protecting gains made during the hospitalization.

Criteria for return visits and staying in the SE-AN program

Following discharge from a SE-AN hospital stay, patients are encouraged to immediately begin working towards the goals they set at intake to improve the quality of their life, adhere to their meal plan, and stay medically stable. If, after three months, the patient has been able to meet all of their goals, the patient should still be medically stable and have maintained their weight. Thus, SE-AN patients can return to treatment for 2–3 weeks to work on potential increases in their meal plan, maintaining their progress, or identify opportunities to enhance medical stability. However, patients who are meeting their goals and feel confident in their ability to continue doing so may choose to wait longer than three months before returning. If medically stable patients wait longer than three months, the expectation is still that they can return to treatment for short term stays if they have remained medically stable and have adhered to their individualized meal plan.

While the program aims to provide a more "doable" treatment option, it is necessary to recognize that there is less of a safety net with a maintenance intervention than a full-weight restoration treatment. The likelihood that there are slips, lapses, or relapses for individuals with SE-AN is still high. However, given the slower pace of treatment, getting back on track requires less effort than when relapse happens on traditional treatment approaches. Thus, the first step for any patient who slips on the SE-AN program is simply returning to their meal plan outlined at discharge. The patient-centered meal plan was created to be doable by the patient using foods they were already eating. Returning to the meal plan, the patient can maintain their current weight and potentially drift back to their discharge weight.

If a patient lapses and cannot maintain their weight, we may request that the patient delay return admission beyond three months and begin working to get back on track with their previous discharge plan to demonstrate that they can maintain their weight and stick to their meal plan outside the hospital. For patients unable to get back on track, we advise they seek treatment for medical stabilization. Once medically stable, if they can get back on track, the patient and treatment team must discuss whether it would be appropriate to return for continuation of the SE-AN program. Just as the creation of this program arose from the ethical considerations regarding continually trying unsuccessful full-weight restoration approaches with individuals with chronic anorexia nervosa, the SE-AN program must fall under the same scrutiny. For patients for whom the SE-AN program did not work, the treatment team and patient must carefully weigh the minimal potential for benefit of continuing in a treatment that has not proven to be effective, relative to the costs of continuing a treatment that is not working, as well as the missed opportunity of pursuing other potential treatments options. The treatment team needs to be willing to discuss all alternative options, including returning to weight restoration approaches or the initiation of palliative, or even hospice, care.

Staff and patient feedback

As reviewed above, there is a dearth of research on effective treatments at higher levels of care for patients with SE-AN. Furthermore, the heterogeneity of the limited existing research impedes the ability to meaningfully synthesize this work and translate it to clinical practice. Meanwhile, patients with SE-AN frequently request admissions for hospital care, and programs must decide, with little evidence to consult, how to best serve these patients. Absent empirical guidance or professional consensus on the best way to serve these patients, we believe that exposing higher levels of care treatment programs to professional scrutiny in order to prompt more in-depth discussion of treatment issues for this population would be beneficial. Additionally, without a generalizable understanding of hospital treatment for patients with SE-AN, program evaluations should be conducted within individual treatment programs to inform strengths and shortcomings of each specific program, from the perspective of the patients and staff. We recently began a quality assessment effort to elicit feedback on our program, in order to further refine and enhance the SE-AN treatment protocol. Below, we provide an overview of staff and patient feedback. Of note, this feedback was given as part of evaluation efforts for our particular program, rather than as part of a methodologically rigorous research protocol, and as such is not intended to create generalized knowledge about hospital treatment of SE-AN.

Staff feedback

Overall, staff feedback about the SE-AN treatment model has been quite positive. Staff responses consistently indicated that the SE-AN model seemed to give a sense of hopefulness for many patients, and provided a good opportunity for us to "meet patients where they're at." Staff acknowledged that this can be a last resort for patients without other options, who are deemed "too sick" or noncompliant and are thus turned away from many other programs. Staff also noted that the greater autonomy given to patients in SE-AN protocol is helpful for their treatment process and progress, and appears to contribute to an increase in effective collaboration between the patient and providers. Staff believe that patients find this approach to be more tolerable, which decreases patient resistance and defensiveness. Finally, staff appreciated being able to individualize treatment

around identifying realistic goals for patients to achieve incremental change outside of the hospital, and felt that in this way they were helping to set the patients up for success rather than contributing to a treatment/relapse cycle.

Staff also noted challenging aspects of the SE-AN treatment model, and areas for improvement. Specifically, several staff noted that explaining this model can be difficult as some patients initially worry that providers are "giving up on them." And although individualization of treatment is generally seen as a strength of the model (by staff and patients alike), staff note that this can also cause issues with consistency and clarity, and for some patients not in the SE-AN program, it can cause an increase in comparisons with others (e.g., patients questioning why other patients are allowed certain accommodations, but they are not). A third challenge noted was that some patients do not use the treatment model effectively. For example, doing it to placate family or outside providers by "doing treatment," but without genuine collaborative intent, is inconsistent with the model. Finally, this model can lead to significant challenges when patients (and/or their families and outside providers) do not have a realistic understanding of the severity of and impairment from their disorder, which can cause disagreement between the patient and their team regarding what goals are realistic. For example, a patient who states they want to gain significant weight but is unable to adhere to even a maintenance meal plan while in the hospital, would be required to set a more realistic goal. Treatment staff indicated that patients can at times get fixated on the parameters of the SE-AN model, and consistently challenge the SE-AN model limits (e.g., on length of stay, being asked to set more realistic goals); working through this reactivity and conflict detracts from providers being able to more meaningfully work on the eating disorder itself and provide patients with the full benefit of this model.

Patient feedback

Overall, patient feedback has been positive, though somewhat more mixed than staff feedback. Generally, patient and staff feedback show good correspondence, with both groups noting similar strengths and weaknesses of the treatment model. On the positive side, patients voiced appreciation for the autonomy and individuality that this approach provided with regards to being able to tailor their goals to what is specific for them. Patients stated that they "felt heard" and that their team collaborated well with them. As one patient stated "I don't need to have a 4-hour panic attack over…lasagna which I'm never going to eat outside treatment. It just made sense to me working on what I wanted to work on." Patients described the program as "realistic" and "autonomy supporting" and "humane" because it is "not forcing something that's not worked in the past. And it's not forcing, like, the cookie cutter model on a person, because every person is unique." One patient with a trauma history stated that being given autonomy over her own choices while being kept safe from her ED was like "nothing I've experienced before and I think so incredibly healing." Another patient highlighted that "people with AN often desire a high need for control. This program helps give us some level of control while working on difficult recovery goals…. This is the first time where I feel like I am in control of my recovery. I'm no longer scared I am going to die. I am no longer going to the ER 1–2 times a week…. It really seems to be working."

Some patients were conflicted on the theoretical approach to treatment. For example, one patient expressed appreciation that "skills are repeatedly used to help facilitate success on the outside" [outside the hospital], while another patient stated that "more of the process work could be utilized rather than skills over and over" because "if you're on the SE-AN track you probably have learned that before and probably done those groups a million times."

Patients struggled with the structure of the treatment model. Some stated that they "wish it was faster" though they know "this is the speed it has to be for me." Patients also expressed a desire for even more individualization, though also acknowledged that it can be difficult to balance individualization and consistency. One patient stated that she has seen other patients "just messing around" and "not actually working…just doing your disorder in treatment." So, while patients understand the need for structure and limitations, they tend to think those limits make sense in general and for other patients on the SE-AN model, but should be less rigid for themselves. Patients discussed feeling worried that they may not be allowed to return if they struggle and are unable to meet their goals in between hospital stays, which highlights the difficult balance between requiring patients to demonstrate that they are being helped by the treatment model (to ensure we are not enabling stagnation and continued disorder) while also making allowances for non-linear recovery processes. Patients also expressed that the SE-AN model can feel limiting. One patient stated that as a result of the SE-AN treatment model she had "lower expectations for myself" and felt the "agenda for this stay was tainted by previous stays" and that "once labeled, no matter your willingness to move forward, regardless of want to go further, it's shut down." Several patients similarly commented that being "labeled" as SE-AN and being recommended to the SE-AN treatment model was originally hard as it made them feel hopeless and given up on, but that once the goals of this approach were more clearly communicated, they understood its value better. Finally, patients noted some concern about

lack of community resources and understanding of this approach, with one patient stating "I am scared that other treatment programs won't take an approach like this. It can also be hard to get my outpatient providers to understand the program."

Staff and patient feedback takeaways

Overall, staff and patient feedback suggest that the SE-AN treatment protocol is beneficial in many ways, especially in providing a treatment option—one that has the potential to extend life and willingness to engage with treatment—for those who are "too sick" for other treatment or who feel they cannot tolerate or do not want full/traditional recovery. Areas for potential improvement have been highlighted. Specifically, further consideration should be given to balancing individualization with consistency and having clearer guidelines for when, and with whom, to hold rigid expectations and under what circumstances greater flexibility can be extended. It will be important to continue to develop better strategies to communicate clearly and collaboratively with patients around what being classified as SE-AN means and the potential benefits of the SE-AN model in a way that can instill hope rather than hopelessness. Also, greater attention should be paid to addressing patient dissatisfaction when they feel limited by the SE-AN model but may not be able or willing to do traditional treatment with full weight restoration. Finally, thorough integration of the SE-AN program with outpatient providers is critical, but it can be challenging to find outpatient providers who will accept patients with SE-AN and who will agree to work on the patient's SE-AN goals rather than traditional recovery goals and weight restoration.

Summary

In summary, we have provided a brief overview of SE-AN both scientifically and clinically. We have also attempted to highlight the limited empirically supported treatment options for SE-AN, but wish to underscore that this dearth of treatment options is significantly pronounced at higher levels of care. Given the severity of SE-AN, it is a simple fact that these patients will often use hospital-based services, and thus, greater attention to this deficit is encouraged.

Our program developed a structured treatment program for SE-AN which highlights flexible goalsetting, high levels of collaboration between patient and clinical staff, and an emphasis on enhancing quality of life, medical stability, and adequate nutritional rehabilitation. Furthermore, the approach highlights the importance of tailoring treatment planning to a given patient and their collaboratively established goals. Explicit treatment contracts are developed with patients and include a shared understanding of targeted objectives. Additionally, there is a significant effort to develop a detailed plan for maintaining health and returning to treatment after discharge from the hospital. This may include future "booster" admissions for limited periods of time to assist patients in continuing to maintain, or incrementally advance, health related goal achievement. Presently, our survey of patients, and staff suggest that the program offers significant advantages for both the treatment team and the patient, but also the continued challenges that a program for SE-AN in a hospital environment must face. We would strongly recommend that clinicians and scientists work to establish empirically supported approaches to treating patients with SE-AN in a hospital environment. Given this is a necessary type of care for such patients and the very serious nature of this illness, it is worthy of such an investment.

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