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Towards collaborative care for severe and enduring Anorexia Nervosa – a mixed-method approach

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Abstract

Background Severe and Enduring Eating Disorders (SEED), in particular SEED-Anorexia Nervosa (SE-AN), may represent the most difficult disorder to treat in psychiatry. Furthermore, the lack of empirical research in this patient group, and, consequently the lack of guidelines, call for an urgent increase in research and discussion within this field. Meanwhile experts concur that effective care should be structured in a collaborative manner.

Objective To identify the challenges in providing care to patients with SE-AN in the Dutch healthcare context, and propose a collaborative care treatment model to address these issues.

Methods A pragmatic mixed-method approach was used, structured as follows: (1) Identifying perceived barriers and treatment needs from the viewpoint of both patients and eating disorder healthcare professionals through an evaluation questionnaire; (2) Investigating current treatment practices for SEED/SE-AN via benchmarking; (3) Gaining insight into the optimal structure and content of care by interviewing network partners and experts-by-experience. Based on these findings, and drawing from literature on severe and enduring disorders, a treatment model for SE-AN was proposed and implemented.

Results The key challenges identified included a lack of knowledge about eating disorders among network partners, treatment ambivalence among patients and poor collaboration between professionals. The proposed model enhances self-management and collaborative relationships with healthcare providers, offers user-friendly and practical guidance, and aims at stabilization, reducing relapses, deterioration, and readmissions, thereby being cost-effective. Importantly, the model operates across levels of care (primary, secondary, tertiary).

Conclusion This study, describing a collaborative care program for SE-AN, developed and implemented in a highly specialized treatment center for eating disorders, sets the stage for further explanatory/efficacy research to build on the findings in this study, with the following aims: addressing the critical gap in care for SEED/SE-AN, improving better healthcare organization, reducing relapse rates, and lowering costs for this often overlooked patient group.

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Plain English summary

Severe and Enduring Eating Disorders (SEED), and particularly Severe and Enduring Anorexia Nervosa (SE-AN), present significant challenges in psychiatric treatment. This study aimed to understand the obstacles in caring for patients with SEED/SE-AN in the Dutch healthcare system and proposed a collaborative care model to address the issues. Through surveys, interviews, and benchmarking, key challenges were identified, including limited knowledge about eating disorders, patient ambivalence, and poor professional collaboration. The collaborative care model for SE-AN that was proposed in this study emphasizes structured care coordination, education for network partners, and support for eating disorder professionals, combining clinical management and psychotherapy. The study aims to bridge the gap in care for SE-AN and improve healthcare organization for this overlooked patient group.

Keywords Severe and Enduring Eating Disorders (SEED), Severe and Enduring Anorexia Nervosa (SE-AN), Eating disorders, Collaborative care, Chronicity

Background

Eating disorders (ED) are associated with great functional impairment and high mortality rates. Specifically, anorexia nervosa (AN) has the highest mortality rate of any psychiatric disorder [1]. More than 70% of patients with EDs have comorbid psychiatric disorders [2], which are linked to a worse prognosis and a higher chance of chronicity [3]. Of all patients with AN or bulimia nervosa (BN), roughly 20% develop an enduring illness [4]: a so-called 'severe and enduring eating disorder' (SEED) [5]. The consequences of SEED on quality of life are comparable to those experienced by patients with other severe enduring psychiatric illnesses, such as schizophrenia [6]. Daily life is constrained by chronic psychiatric symptoms, and there is usually significant psychological distress. This results in an increased need for healthcare services [7]. Furthermore, SEED, especially SEED-Anorexia Nervosa (SE-AN) has serious physical repercussions and patients often live on the edge of what their bodies are able to cope with [8]. Patients can remain stable for many years at a low BMI, but any extra stress on the body (for example due to an infection or purging behavior) that could affect weight or other clinical features, such as potassium levels, can lead to physical decompensation fast [6]. Previously, a call to action was issued, highlighting the significant lack of evidence-based treatments, insufficient research, and overall neglect within the domain of SEED [5].

Another problematic issue is the lack of consensus regarding the definition of SEED. This ambiguity leads to inconsistent participant recruitment for studies, which hinders the increase of knowledge about this group of patients, and contributes to the potential misdiagnosis of patients [9]. First, criteria for determining cut-off points for the duration of SEED vary widely, with cut-offs ranging from 5 to 10 years [10, 11]. Second, although the SEED category implies multiple unsuccessful treatment attempts, there is no agreed-upon standard regarding the number, quality or focus of these previous interventions [5]. Other variables often taken into consideration

when defining SEED are severity of illness and patient age [5]. A refined classification of the SE-AN subcategory was suggested by Hay and Touyz [12]. This classification is more aligned to definitions of other enduring psychiatric illnesses, yet it diverges from the most often mentioned cut-off points and for example mentions a duration of only >3 years [12], although a cut-off of 7 years has also often been used for SE-AN [13–15]. Other criteria include a persistent state of dietary restriction, underweight, and overevaluation of weight/shape with functional impairment; exposure to at least two evidence-based treatments appropriately delivered together with a diagnostic assessment and formulation that incorporates an assessment of the person's ED health literacy and stage of change. Robinson furthermore suggested including service utilization in the definition of SEED. These differences underline the lack of an agreed upon definition [16].

Although ED treatment usually focuses on recovering from ED symptoms and, in case of AN, weight restoration, for patients with SE-AN the emphasis lies on maximizing medical stability, quality of life, social adjustment, and vocational issues [5]. Recovery is in fact still possible for some patients if they reach a certain motivational tipping point [17]. Eddy et al. showed that around a third of patients with AN recover in the first decade of their illness, but that a second third will still recover during the second decade [18]. Several potentially beneficial treatment options for patients with SEED/SE-AN have been identified, for example, motivational treatment, (SEED-adapted) enhanced Cognitive Behavior Therapy and Specialist Supportive Clinical Management (SSCM[-SE]) [19, 20]. SSCM combines active clinical management (including information, advice, and encouragement) with psychotherapeutic elements, marked by a supportive therapeutic style. SSCM-SE is a modified version for patients with SEED and prioritizes quality of life and harm minimization, but weight gain – unlike the standard form SSCM – is not a primary aim [14]. Other treatments that have been mentioned as potentially beneficial

are pharmacological treatments and brain stimulation therapies [19].

Patients with SE-AN present a highly complex clinical picture, characterized by a mix of acute and long-term symptoms that tend to worsen over time. Managing such patients necessitates a multidisciplinary team approach, as well as collaboration with network partners across various levels of care (primary, secondary, tertiary). This collaborative effort should also involve the patients themselves and their caregivers. The importance of coordination and collaboration among all healthcare professionals involved cannot be overstated, given the likelihood of comorbid conditions and evolving treatment priorities. Moreover, this collaboration is essential to ensure that professionals remain vigilant and continuously monitor the patient's risk.

While recognizing the necessity of a systematic approach to treating SE-AN and fostering collaboration among all stakeholders, there is a notable gap in implementing an organized treatment model for SE-AN. However, insights from literature, including literature on other complex and chronic patient groups, such as those with severe personality disorders [21], offer valuable strategies for organizing care.

The Collaborative Care Model (CCM) [21] offers valuable insights into the organization of care and a framework for collaboration. Underlying principles are shared decision making, creating effective collaborative relationships (with all parties involved), increasing self-management and enhancing problem-solving skills. It increases self-management, reduces self-destructive behavior, and improves quality and continuity of care [22]. Within this model, nurses serve as collaborative care managers, ensuring optimal continuity and coordination of care [5]. Second, the Community Outreach Partnership Program (COPP) [23] places less emphasis on diminishing ED symptoms and more on improving quality of life through fostering independence and establishing a social support network beyond the healthcare system. Key elements in the treatment plan include the so-called non-negotiable agreements, which are primarily intended to ensure medical safety.

The main aim of this study was to define a model that can improve the quality and continuity of care for patients with SE-AN within the context of Dutch mental healthcare. Our highly specialized ED treatment center offers a supra-regional treatment function and provides specialized mental health care services, as well as high-intensity and highly specialized matched care treatment programs for patients with ED, including those with severe and complex ED. The model was defined, taking the literature reviewed above into account, and by (1) identifying the perceived barriers and treatment needs from the viewpoint of patients in treatment at our center

and our own ED healthcare professionals, by (2) investigating the current treatment practices with regards to SEED/SE-AN in other ED centers in the Netherlands, and by (3) gaining insight into the optimal structure and content of care for patients with SE-AN by interviewing network partners collaborating with ED centers (e.g., general practitioners [GP's], dietitians) and experts by experience. These results led to a proposed treatment model for patients with SE-AN, which we implemented in our treatment center. We illustrated the potential efficacy of this model with two patient cases, before and after implementation.

Method

Several steps were taken to define a proper treatment model for patients with SE-AN.

First, to address the challenges in treating patients with SE-AN, and ED more in general, individuals undergoing outpatient group treatment (regular daytime group treatment or SE-AN treatment) or inpatient care at our ED treatment center at the time of the study were contacted to complete a short evaluation, forming a convenience sample. This survey aligned with our usual treatment evaluation and consisted of five short questions (regarding the alignment of treatment with patients' expectations; consideration of patients' needs and wishes regarding treatment planning; and any gaps patients perceived in their current treatment) with ordinal-level responses and an option to provide additional comments. The survey was distributed over a short period of two weeks by an independent staff member who was not involved in the research, without any additional reminders. ED healthcare professionals working in inpatient as well as outpatient treatment (and some worked in both settings) from our treatment center completed a similar evaluation survey. The completed surveys were submitted voluntarily and anonymously. Insights gained from these evaluations informed the development of a topic list for further open-ended questionnaires and interviews, facilitating a deeper exploration of issues in subsequent phases of the study. Unlike the treatment evaluations that were based on both ED treatment and SE-AN treatment, subsequent phases of this study only focused on SE-AN.

Second, benchmarking was utilized to explore how various mental health care institutions design care for patients with SEED/SE-AN (see Supplement 1) [24]. Three organizations delivered Top Clinical mental healthcare, two delivered specialized mental healthcare. In the Netherlands, mental healthcare is organized according to severity. Top Clinical mental healthcare offers highly specialized treatments and includes a focus on innovative treatments and (implementation and dissemination of) disorder-specific scientific research. Another focus of Top Clinical mental healthcare is consultation and

offering second opinions to other treatment centers. Specialized mental healthcare is for severe or chronic mental health problems with treatment durations up to a year, with possibility of extensions.

Third, network partners actively involved in the care of patients with SEED/SE-AN were invited via email or telephone to contribute to the study through an open-ended questionnaire (see Supplement 2). To ensure comprehensive representation from all disciplines involved in SEED/SE-AN patient care, invitations were extended to 14 general practitioners' offices, 5 FACT (Flexible Assertive Community Treatment) team members, 2 dietitians, 2 nurse specialists, and 2 sociotherapists. Reminders were sent to improve the response rate.

Fourth, semi-structured interviews with two experts by experience from a self-help organization were conducted to gain insights into the optimal structure and content of care for patients with SEED/SE-AN. Interviews were conducted based on the topic list that resulted from the treatment evaluations by patients and ED healthcare professionals (see Supplement 3).

Results

Treatment evaluation by patients and ED healthcare professionals

Of the 71 approached, 35 patients completed the treatment evaluation. The sample represented the diverse patient population in treatment at our ED treatment center (daytime group treatment, inpatients and outpatients), and 17.1% were patients with SE-AN. Of particular interest, patients with SEED pointed out they needed more individual treatment time, more frequent group sessions, and creative therapies.

Of the 43 staff members that were approached, 27 completed the evaluation. Several needs were mentioned: the need for more individual treatment options, supportive and structuring treatment options, as well as the need for scaling-up treatment. Staff also mentioned difficulties

in the transition from inpatient to daytime treatment. Treatment should focus more on symptom reduction, acceptance of the illness, quality of life, and the treatment should convey that the patient is understood and acknowledged. Services available to patients with SEED are currently too limited, and collaboration with network partners is insufficient. Staff furthermore needs support in boosting patients' self-management in physical, psychological, and social areas.

Benchmarking

All five ED centers participated in the benchmarking, emphasizing person-centered care. They noted that customized care is essential for patients with SEED/SE-AN, who often find standard treatments insufficient. Two institutions used SSCM, involving supportive treatment, physical monitoring, nutritional management, and psychoeducation. Other institutions' approaches aligned with SSCM, though not explicitly named. One organization specifically employed CBT-E.

The organizations aim to enhance quality of life, focusing on rediscovering joy, maintaining social connections, and finding meaningful activities. Treatment also targets stabilization and harm reduction, minimizing the ED's impact and preventing deterioration. Most have diverse disciplines in-house for integrated care. A robust support network, involving regular external consultations, is deemed critical, though no specific collaborative treatment model was mentioned. The collaboration's success depends on patient needs and practitioner willingness to collaborate. Three institutions viewed SEED/SE-AN treatment as applicable to both specialized and primary mental health care. Stable patients without improvement could move to primary care, with an easy return to specialized care if needed. Two institutions argued SEED/SE-AN care belongs in specialized care due to primary care's lack of expertise, suggesting specialized care could help enhance knowledge in primary care so that patients can be referred to specialized care more often.

Table 1 Points for improvement in SEED care according to network partners

| Collaboration | Treatment |
|--|---|
| The specialized ED treatment center should take the initiative to improve collaboration | Personalized outpatient treatment and clinical admission when necessary |
| Better and more frequent collaboration w.r.t. treatment plans, treatment evaluation and coordination of care | Accessible scaling-up of treatment when needed (increase of symptoms, risks) |
| Face-to-face consultation | Timely professional help |
| Increasing the knowledge w.r.t. possibilities and limitations of specialized care | Shorter waiting-lists |
| Expertise development for professionals outside specialized care | Low-frequent but long-term follow-up by specialized care in collaboration with basic mental health care, GP, etc. |

Network partners

The survey received a 32% response rate from network partners. Respondents were non-ED professionals, more specifically general practice-based nurse specialists (4), nurse specialists (2) and one sociotherapist and dietitian. Points for improvement are presented in Table 1.

Experts by experience

The experts by experience viewed the term "severe and enduring ED" negatively, suggesting it implies abandonment and a lack of potential for recovery. They argued the definition of SEED applies when recovery seems unattainable, but caution against declaring further recovery impossible, especially if correct treatment was previously

unavailable. Maintaining and conveying hope is crucial; they noted recovery is possible even after many years. Patients sense when providers lose faith in improvement, potentially harming the therapeutic relationship, which they deem essential.

Respondents advocated for care tailored to individual patient needs, criticizing one-size-fits-all approaches and stressing the importance of listening to patients. They emphasized empowerment and autonomy, focusing on identifying underlying issues and aiding patients in leading as comfortable a life as possible. They interpret referrals from specialized to primary mental health care as signaling a patient has been given up on, suggesting it diminishes their worth and overlooks the root of the problem. The lack of ED expertise in primary care is problematic. However, they conceded referral to primary care might be feasible for stable individuals, provided specialized care remains vigilant due to the fluctuating nature of EDs and the risk of relapse during transitions. Improving collaboration and communication among care providers is important. They envisioned an ideal scenario where each patient has a multidisciplinary team regularly reviewing their progress, though they recognized the challenges in implementing such a model. They suggested involving experts by experience in patient groups can significantly enhance understanding and support for patients with SEED.

Development of the collaborative care treatment model

The CCM [22] model fits several needs as mentioned in the questionnaires and interviews, such as shared decision-making, increasing self-management, and actively involving all stakeholders. Collaboration between network partners across all care levels is essential. Active clinical management with psychotherapeutic elements, as incorporated in SSCM-SE is also required [14]. Finally, the COPP [23] prioritizes enhancing quality of life through independence and social support outside the healthcare system.

To integrate these elements effectively, we adopted the CCM model as our foundation and enriched it with components from SSCM-SE and the COPP. The resulting model enhances self-management and collaborative relationships with healthcare providers, offers user-friendly and practical guidance, and aims at stabilization, reducing relapses, deterioration, and readmissions, thereby being cost-effective. Importantly, our collaborative care model operates across levels of care (primary, secondary, tertiary).

The resulting model is divided into three phases, encompassing five integrated elements, see Fig. 1. An explanation of each phase is described in the following paragraphs. After that, two cases are presented

illustrating the situation before and after implementation. Both patients provided their consent for including their case description in the present paper.

Phase 1: Preparation

This phase is dedicated to establishing connections, introduction of the CCM, and setting up arrangements with the patient, their caregivers, and the network partners involved. We use the definition of Hay and Touyz [12] to determine the eligibility of patients for the program, but with the often-used cut-off of 7 years for the duration of AN [13–15] and at least two previous unsuccessful evidence-based treatment attempts, and additionally one treatment or second opinion at a Top Clinical mental healthcare institution. Exclusion criteria are somatic instability requiring acute medical care or inpatient treatment, and inability to set non-negotiable agreements, as treatment is voluntary. The specialized ED center takes the lead in coordinating the collaboration among all parties. During this phase, it is important to define and document the frequency and content of contacts, as well as the roles each participant will play. At our center we offer a separate group and individual treatment for patients with SE-AN (next to regular treatment for ED). Goals are set using a person-centered approach and shared decision-making; while these goals primarily reflect the patient's values and norms, ensuring safety is paramount. Therefore, a crisis plan regarding medical and psychological safety is developed in collaboration with the patient prioritizing the least restrictive option. This plan contains non-negotiable agreements, such as specific thresholds for weight loss or critical abnormalities in lab results, early signs of a crisis, the most appropriate treatment setting (booster clinical treatment at our treatment center, admission to a general hospital or an inpatient psychiatric unit, for example) in these cases, and the corresponding interventions that will be enacted.

Phase 2: Treatment

Phase 2 focuses on monitoring the patient's physical and mental condition, identifying potential risks, and initiating appropriate interventions. In this phase, the patient actively participates in designing a relapse prevention plan. Recognizing early signs of relapse and preparing practical coping strategies are key components of this plan, enhancing the patient's ability to manage their condition. While the patient takes the lead in in this planning, therapists and caregivers have access to the crisis plan to ensure a coordinated response when needed. The focus of nutrition is on health and safety, not on weight gain, unless requested by the patient.

Another key objective of Phase 2 is to work gradually towards realistic treatment goals within a continuum of care at a pace comfortable to the patient. This may

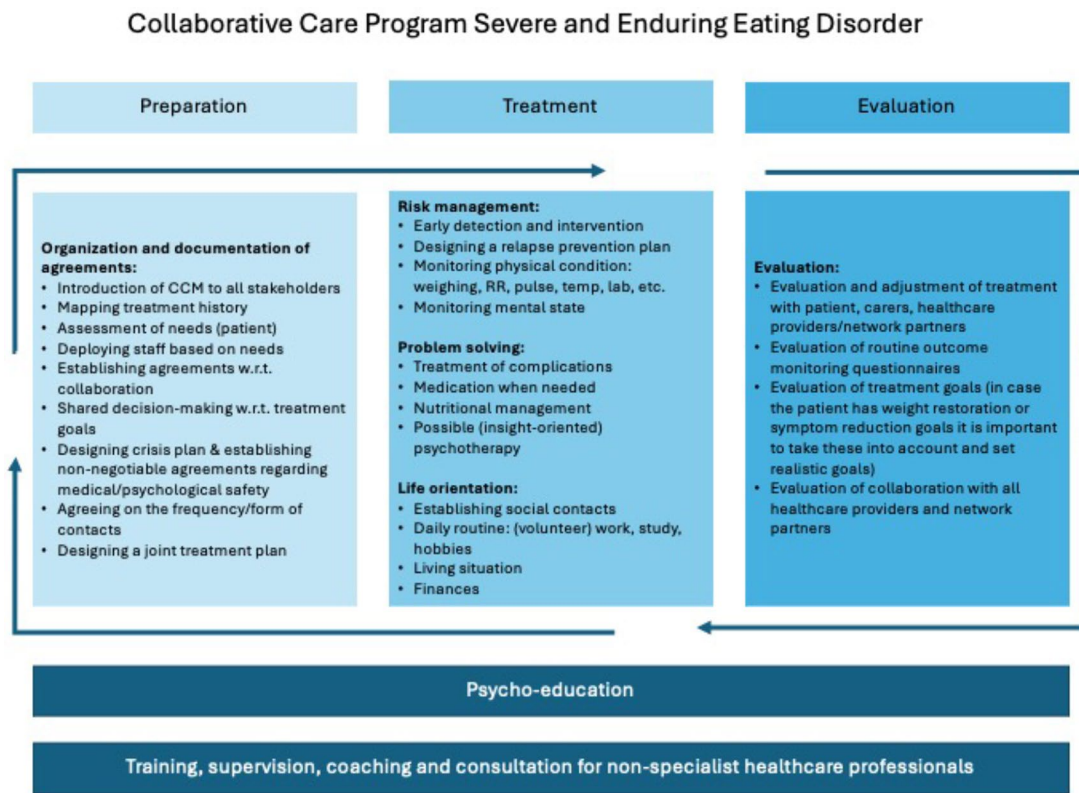


Fig. 1 Collaborative Care Program for SE-AN

include our SE-AN group or individual treatment, possibly combined with food management, and treatment for any comorbid conditions. Psychotherapy for comorbid disorders and pharmaceutical treatment can be included, depending on the patient's needs. From Phase 1, it is already determined which network partner will be involved with each specific treatment goal and in which treatment setting. Scaling-up and scaling-down of treatment for the ED (inpatient, day programs or partial hospitalization and outpatient) is possible, matching the individual level of motivation for change with goals of treatment. This enables patients with different types and degrees of severity to be included in the program. Considering the significant impact of SE-AN on patients' quality of life, issues such as housing, occupation (employment, education), relationships (social, family), and finances require attention. Effective resocialization strategies are critical as they help diminish the influence of the ED on the patient's life, thereby increasing stability and overall quality of life. When treatment shifts from focusing solely on reducing ED symptoms and risk management to enhancing quality of life, ED symptoms may still improve.

This person-centered approach of our treatment also stresses the importance of dignity, respect, and compassion in interaction, aiming to empower patients, and

create and maintain hope. The need for treatment to embrace hope for a realistic, self-defined recovery means acknowledging that recovery might not always align with conventional or idealized, or even self-defined desirable outcomes. For some individuals with SE-AN, this could involve "attaining peace from suffering," which may include the possibility of a "dignified death." Discussing this topic, while maintaining hope for full recovery does not bring death closer, but paradoxically, it can open up new possibilities for life and diminish suicide risk.

Phase 3: Evaluation

Phase 3 concerns evaluation of the treatment. This evaluation should be repeated periodically, at a minimum of every three months. The criteria for evaluation, as established during Phase 1, should include input from all parties involved in the patient's care. Routine Outcome Monitoring Data with special attention to refocusing outcomes towards quality of life is used to provide a comprehensive review of progress and outcomes. If necessary, adjustments may be made to the treatment plan based on these evaluations. The specialized ED center's consultation liaison team (see below under 'Overarching tasks') assists network partners in the patients' care, when patients are no longer in treatment at our treatment center.

Overarching tasks

In Fig. 2, the overarching tasks regarding collaboration and key considerations related to treatment for patients with SE-AN are presented. During the whole process, the specialized ED center has an important job to educate the patient and all stakeholders on the ED, and to assist caretakers in taking care of the patient. The burden of care for ED is high and long lasting and therefore requires continued attention. The specialized ED center furthermore needs to educate network partners about SE-AN/ED. Our consultation liaison team is available daily through a telephone consultation hour to support our network partners, and the team can also be deployed on-site to support the care for patients with SEED. This support extends not only to the (somatic) care of patients with SEED but also to guidance on patient interaction. That is, dissemination of knowledge should not only focus on risk behaviors, possible complications and interventions, but also how to deal with patient’s continuous ambivalence regarding treatment. This ambivalence can cause helplessness, misunderstanding and stigmatizing attitudes in professionals. When patients are confronted with stigmatizing opinions, they may lose trust and hope in treatment, increasing the risk of relapse.

It cannot be overstated how crucial person-centered, personalized treatments, along with the consultation liaison role of the ED treatment center, are in addressing the profound complexity and scientific uncertainties

surrounding SE-AN. Rather than applying a one-size-fits-all approach, this method emphasizes understanding the person living with SE-AN as a whole, while facilitating medical stabilization, harm reduction, quality of life, and the continuous maintenance of hope and engagement with treatment.

When patients are no longer in treatment at the specialized ED center, it is nevertheless important to remain accessible to the patient. This fosters trust and maintains hope. Sometimes, a brief phone call or email contact is enough for the patient to move forward and prevent further relapse. In some cases, a short booster admission may suffice.

Cases

Patient A – before the implementation of the model

Patient A, a married woman in her fifties with a long history of SE-AN, binge eating/purging subtype, was referred back to our clinic by a general hospital. Diagnosed at 16, A. has navigated through cycles of remission and relapse, with additional challenges including an anxiety disorder and post-traumatic stress disorder. Over the past three years, A. had been admitted to our clinic three times with a similar clinical picture. Unfortunately, after her most recent discharge, establishing a follow-up treatment proved challenging, leading to her relapse. This latest episode was particularly severe, with A. nearly ceasing

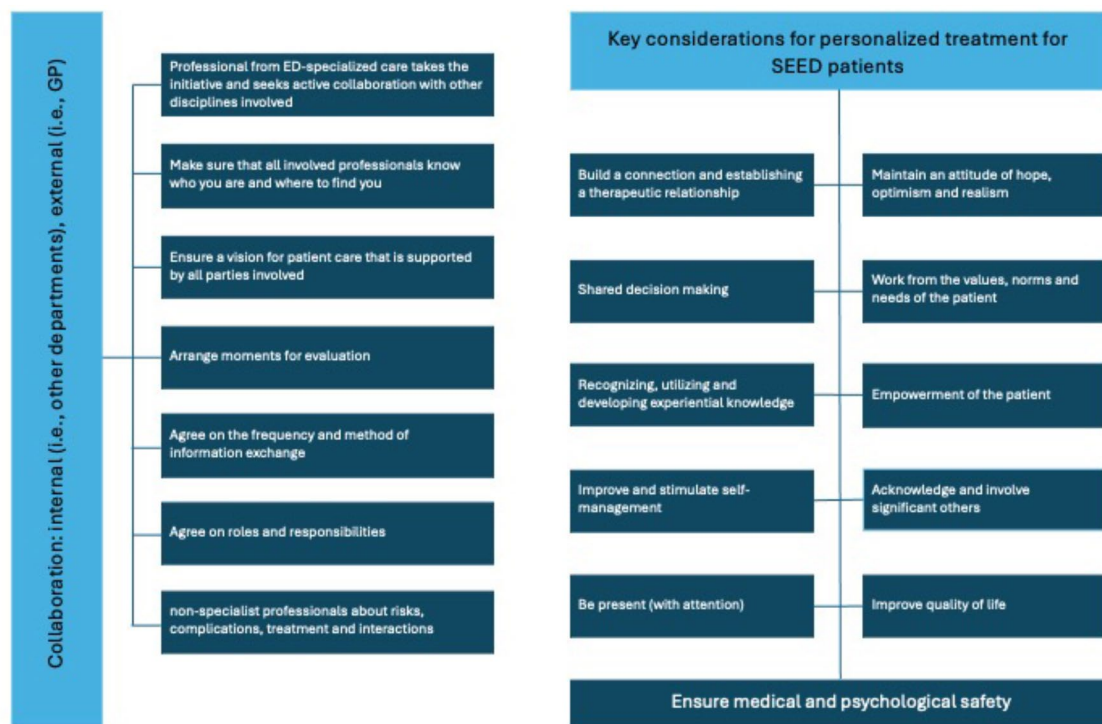


Fig. 2 Overarching tasks and considerations for collaborative care for SE-AN/SEED

to eat, resulting in a BMI of 14, alongside complications from excessive water intake and laxative abuse.

Post-discharge of her previous clinical admission, A. was directed to a FACT (Flexible Assertive Community Treatment) team in her area, aimed at aiding her resocialization and improving her quality of life by helping maintain treatment gains and adapt her eating habits to her home environment. Despite this plan and our efforts to collaborate with her GP for ongoing physical monitoring, the FACT-team felt unable to support A. due to perceived mismatches in their target demographic and a lack of ED expertise.

However, A.'s recent readmission underscored the critical need for effective follow-up care. Despite the difficulties in securing a partnership for her continued treatment, the importance of collaboration among care providers, including A. herself, became increasingly apparent. The need for an ED specialist to offer guidance to those less familiar with SEED and to address stigma, feelings of helplessness, and resistance surrounding the disorder was identified. Educational efforts should extend beyond SEED to include these broader issues.

After detailed discussions about our collaborative care model and the support we could offer, the FACT-team that initially declined involvement agreed to participate in a coordinated care approach. The consensus among us, the GP, and the FACT-team, was that A. required additional support tailored to her home setting. Nevertheless, establishing this network of care encountered obstacles, with multiple rejections stemming from a cycle of referrals, highlighting the complexity of organizing collaborative care for individuals with SEED.

Patient B – an example of a proper implementation of the model

B., a single woman in her thirties, has faced SE-AN, binge eating/purging subtype, for years. Despite multiple treatments since her diagnosis at 20, lasting recovery has eluded her, complicated by comorbid post-traumatic stress disorder and borderline personality disorder. Recent years have seen her losing her job and a relationship ending, with minimal social support from her family and a friend.

Her journey encountered a significant turn during her 6th clinic admission following a severe relapse, characterized by a BMI of 14, minimal food intake, excessive hydration, vomiting, excessive exercise, and laxative misuse. It was then that a collaborative care approach was initiated, involving our clinic's team, a FACT-team, and B.'s GP. This approach led to a comprehensive treatment plan addressing her physical health, psychological needs, and social reintegration, including meaningful daytime activities and home supervision.

An emergency plan was crafted with B., outlining non-negotiable agreements and clear indicators for crisis intervention, which proved pivotal. B.'s engagement in work at a care farm and supervised meals contributed to a stable weight, improved self-esteem, and reduced disordered eating thoughts and behaviors. Two years into this collaborative care, B. experienced a relapse. However, the established emergency plan enabled a swift response, ensuring a short booster admission was sufficient for her to regain stability. The immediate involvement of all network partners facilitated her quick return to societal reintegration, highlighting the effectiveness of coordinated care in managing severe ED.

Discussion

Although AN boasts the highest mortality rate among psychiatric disorders, and SE-AN represents the most severe manifestation within ED, quality and continuity of care for patients with SE-AN is problematic. The lack of systematic treatment organization for SE-AN and lack of empirical evidence leaves many patients inadequately treated. This study aimed to identify treatment challenges for patients with SE-AN utilizing multiple sources of information and proposed a collaborative care treatment model.

After assessing the perceived barriers and treatment needs from the perspectives of patients and healthcare professionals from our own treatment center, analyzing the current Dutch treatment practices for SEED/SE-AN via benchmarking, and gaining insight into the optimal structure and content of care through interviews with network partners and experts by experience, we developed and implemented a treatment model for patients with SE-AN in our highly specialized treatment center. Please note that response rates to the evaluation questionnaires from patients, staff and network partners were relatively low, although similar to response rates in other studies focusing on ED health providers [25–29]. Notably, no GPs responded to the survey. This is partly in line with a previously noted difficulty in obtaining physicians' participation in survey research, due to limited time, lack of interest, insufficient staffing in the office, working in non-educational settings of practice, and stigma [30]. It has been suggested that physicians might be reluctant to participate in studies on sensitive topics or areas of care where they feel their performance may fall short of expectations. Although our findings must be interpreted in the context of a low response rate, this study remains an informative initial examination using pragmatic research methodology to address key questions about how a treatment model can be applied in real-world clinical care. A strength of our study is the use of mixed methods (qualitative and quantitative). Data were collected over a short period within actual clinical care

settings and their evaluation, and from multiple levels of stakeholders, providing a comprehensive perspective. Future empirical research should aim for a more in-depth analysis of the data, which would require a much larger set of primary data.

We incorporated elements from several established treatment models as found in the literature, including SSCM-SE [19, 20], the CCM [21], and the COPP [23]. The model unfolds in three phases, each designed to optimize care for patients with SE-AN. The first phase initiates collaboration among all parties involved, sets treatment goals, and creates an emergency plan prioritizing safety. The second phase concentrates on monitoring the patient's health, identifying potential risks, initiating timely interventions, and treatment focused on realistic goals within a continuum of care. The final phase involves evaluating the treatment efficiency.

The proposed collaborative care treatment model operates across all levels of care - primary, secondary, and tertiary - with the tertiary care center taking a leading role. Consistent with the facilitators for successful implementation of collaborative care as described earlier [31], our model designates one professional to spearhead the process. Given the high complexity and potential medical complications associated with SE-AN, a nurse specialist at the (highly) specialized ED center fills this role. In alignment with the recommendations from Wood et al., the nurse specialist also coordinates inter-professional communication through standardized care pathways and establishes clear boundaries for the role of all network partners [31].

Our collaborative care treatment model addresses the challenges mentioned by patients, staff, network partners, and experts by experience, such as lack of knowledge about ED among network partners, treatment ambivalence among patients, and poor communication/collaboration between professionals. It underscores the importance of educating network partners about ED and managing patients' treatment ambivalence, thereby decreasing often-occurring feelings of helplessness, misunderstanding and stigmatizing attitudes in professionals [32, 33]. The model's structured approach, with clearly defined phases and roles for everyone involved in the patient's care, is designed to improve and ensure continuity of care for patients with SE-AN. This structured framework not only facilitates better care coordination, but also enhances understanding among caregivers, thereby reducing potential miscommunications and inefficiencies.

Our two case examples also illustrate the significant lack of knowledge about ED among network partners. Beyond the organization and coordination of treatment, specialized ED centers play an important role in education. This includes providing insights on handling the

pervasive ambivalence towards treatment often experienced by patients. The interviews and case examples also showed that communication and collaboration between network partners is often poor. Wood et al. mention that healthcare tends to operate in silos and staff and organizational attitudes to integration are important to take into account [31]. The complexity of SE-AN exacerbates these challenges, underscoring the need for comprehensive education and support for all professionals involved in patient care.

Conclusion

This study, describing and implementing a collaborative care program for SE-AN, sets the stage for further research into its implementation effectiveness and cost-efficiency. It highlights the importance of directly assessing patient perspectives on collaborative care. Despite known implementation challenges, as seen in depression care, identifying and addressing barriers to collaborative care is important for expanding access [34]. Wonderlich et al. described the limited understanding of SEED as "a crisis in our field", noting that the most severely affected patients often receive the least adequate care [5]. Given the study's limited generalizability, there is a clear call for future research to build on our findings, aiming to address the critical gap in care for SE-AN, improve better healthcare and healthcare organization, reduced relapse rates, and lower costs for this often overlooked patient group.

Abbreviations

| | |
|-----------|---|
| AN | Anorexia nervosa |
| BN | Bulimia nervosa |
| CBT-E | Enhanced Cognitive Behavior Therapy |
| CCM | Collaborative Care Model |
| COPP | Community Outreach Partnership Program |
| ED | Eating disorders |
| FACT | Flexible Assertive Community Treatment |
| GP | General practitioner |
| SSCM(-SE) | Specialist Supported Clinical Management (for SEED) |
| SEED | Severe and enduring eating disorders |
| SE-AN | Severe and enduring anorexia nervosa |

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40337-024-01091-z>.

Supplementary Material 1

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Author contributions

Ilona v/d Eijnde-Damen: Data curation; Formal analysis, Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing. Joyce Maas: Writing – original draft; Writing – review & editing. Pia Burger: Writing – original draft; Writing – review & editing. Nynke Bodde: Writing – original draft; Writing – review & editing. Mladena Simeunovic-Ostojic: Conceptualization; Methodology, Supervision; Writing – original draft; Writing – review & editing.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations**Ethics approval and consent to participate**

The study was not subject to the Medical Research Involving Human Subjects Act. Participants signed informed consent before participation.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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