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SEED-AN and a non-specialised, severe mental illness (SMI) community treatment model: perspectives of professionals and patients of a QoL-focussed treatment

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Abstract

Background Improving care for SEED-AN patients is urgently needed. Current specialist eating disorder (SEDU) programs have minimal impact, resulting in poor quality of life. Flexible assertive community treatment (FACT) focuses on improving the quality of life of people with severe mental illness.

Aim This study systematically examined professionals' and patients' experiences with existing care for SEED AN in two settings in two health districts in the Netherlands. Specifically, the specialised Eating Disorder Unit and FACT.

Methods A qualitative approach was used: Twelve professionals participated in focus groups, and four professionals and six patients were interviewed individually. Reflective thematic analysis was used to analyse the data.

Results Four themes were constructed: "We feel ignorant in the treatment of SEED-AN patients"; "There is a disability to act"; "We are more than executive practitioners alone"; and "The professionals at FACT have given me back my confidence in treatment". The findings reflect how support for SEED-AN patients is provided by both FACT and SEDU professionals and how SEED-AN patients experience the FACT approach.

Discussion A resource group model promotes collaboration among professionals, patients and the patient's support system. The model is expected to increase knowledge about SEED-AN among stakeholders who support the quality of life of SEED-AN patients.

Plain English summary

Of the group of patients diagnosed with anorexia nervosa, approximately 20–25% develop a severe and persistent eating disorder - anorexia nervosa (SEED-AN). Families, spouses and carers struggle with a range of emotions and challenges associated with this form of the disease. Current specialised programmes often focus on the recovery of younger people. In the Netherlands, people with severe mental illness can be supported by specialised outpatient

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teams. These teams are often trained in the Flexible Assertive Community Treatment (FACT) method. In addition to treating the disorder, the method focuses on improving quality of life in several areas, such as social participation, work, independent living and leisure. Patients with SEED-AN are often excluded from such programmes, but could benefit from the method. With this study, we have gained a better understanding of why most of the patients with SEED-AN have not been able to use these services. Both professionals and SEED-AN patients shared their experiences and opinions. Our findings reveal a number of challenges, such as the unfamiliarity of professionals with eating disorders, but also the perceptions of SEED-AN patients who do receive this support. Collaboration between patients, professionals, family members and other supporters was considered crucial. Our recommendation is network development, the use of a resource group model appeared to be helpful in this.

Keywords Anorexia nervosa, SEED-AN, Reflexive thematic analysis, FACT, Resource group model

Background

Over a period of three decades, the number of cases of anorexia nervosa in the Netherlands has remained stable; nevertheless, during the COVID-19 pandemic, the diagnostic incidence of anorexia in Western countries was higher in 2020 and steadily increased from March 2020 to 1.5 by the end of that year [1]. However, there seems to be an improvement in the recognition of eating disorders, possibly through greater public awareness and better diagnostic tools [2]. A significant proportion of people diagnosed with anorexia nervosa develop a longer duration of the disorder, despite treatment according to guidelines [3]. These patients reported negative effects of therapy and admission to a psychiatric institution [4]. Unfortunately, the risk of dying because of an eating disorder is high [5, 6]. Recent research has shown that the mortality rate of people with AN can be up to five times higher [2], with one in five people dying by suicide [5]. Approximately half of people with an eating disorder experience partial recovery [7–9]. A Dutch study [3] described partial recovery in adolescents on the basis of a reduction in clinical symptoms, such as BMI, degree of functional disability and need for supervision in anorexia nervosa specifically, as described in the Eating Disorder Examination (EDE) [10, p. 265–308]. However, 30% continue to have one or more symptoms, and 20–25% have a long-lasting form of anorexia nervosa in which both physical and psychological complications have a negative impact on quality of life [7, 11, 12].

There is also an ongoing debate about the definition of severe and enduring eating disorders [4]. A recent meta-analysis posed alternative conceptualisations of the issue, considering treatment options and complex intra- and interpsychic processes of SEED-AN [13]. In our study, we use the term SEED-AN to exclude other types of long-lasting eating disorders to improve the approach [14]. Owing to a lack of international consensus, this study used the criteria in the Dutch Eating Disorders Standard; individuals are considered to have a chronic illness if AN is present continuously for 5 years or intermittently for 10 years [15].

Living with SEED-AN can have a serious impact on an individual's quality of life, leading to psychological problems such as depression and anxiety, as well as problems with memory, concentration, eating, weight and appearance [16]. The poor nutritional status associated with anorexia can lead to serious physical complications, such as heart problems, irritation of the bowel and esophagus, and erosion of tooth enamel [14, 17]. In addition, living with SEED-AN has a negative effect on an individual's social life [18]. Patients may feel that they are a burden to those around them and to healthcare providers [18–22]. Many patients are unable to study or work, which can lead to social isolation. As a result, they become dissatisfied with their lives in many areas, including health, sexuality, finances, leisure and social status. Some patients therefore live in poor physical, psychological and social conditions [18, 22, 23]. A quotation published in 2019 illustrates this:

“Dear friends,

No one has failed to notice that my health is getting worse, despite my attempts to feel better in all sorts of ways. Sometimes I seem to have found the solution, but 10 steps forward always seem to end up in 20 steps back.”

Sandy, 2019 [18, p. 35].

Overall, eating disorders are serious but treatable illnesses. Early treatment, such as family-based therapy (FBT) [24] for young people, has good outcomes. Although long-term outcomes are limited, early treatment reduces risk factors such as body dissatisfaction and low self-esteem but also promotes help-seeking behaviour and symptom recognition [25, 26].

Unfortunately, eating disorders are also the most common chronic disorders among young people [3]. The Health Council of the Netherlands has therefore recommended a unified national approach focusing on prevention and early treatment [27]. Evidence-based treatment methods are still limited; the Dutch guidelines [15] suggest an individualised plan that includes collaboration

with family caregivers and/or expertise care. Current treatment options include psychological interventions, the treatment of physical complaints, pharmacotherapy, or a combination of these approaches. These treatments are available in a specialist setting (specialised eating disorder unit [SEDU]). Treatment for AN initially focused on restoring physical health and normalising weight and eating behaviour, and current treatment programmes address mainly the physical and psychological symptoms of patients with a more acute form of anorexia nervosa. These treatments seem to be more effective in younger patients with a shorter duration of illness; therefore, they do not fully address the needs of patients with SEED-AN [28, 29], namely, reducing persistent negative effects on quality of life [13, 14, 18, 23, 24].

In addition, SEDU professionals are increasingly confronted with the demand for nonspecific medical and sometimes palliative support from persons suffering from SEED-AN [30]. On the basis of the findings concerning who strongly influences quality of life, it seems reasonable that persons with SEED-AN require a different approach. Touyz et al. [22] adapted the Specialist Supportive Clinical Management Model (SSCM) [31, 32] to SEED-AN and compared the approach with CBT-E [10]. An adapted treatment paradigm was proposed; the focus should shift from complete recovery to improving quality of life and avoiding experiences of treatment failure [22, 33].

Approximately 20% of the persons diagnosed with AN remain chronically ill [9]). Unfortunately, there is no evidence-based treatment for SEED-AN [34]. Some SEDUs offer specialised help, such as group sessions, often led by a therapist and/or experienced individuals, with the aim of recognising and acknowledging the common issues (e.g., problems responsible for a diminished quality of life, physical healthcare issues) within SEED-AN [35]. Furthermore, clinical pathways are offered on the basis of SSCM [31, 32]. SSCM can improve motivation and quality of life to support recovery from the core pathology of anorexia. However, there is still insufficient knowledge about which SEED patients benefit from weight restoration versus focusing on quality of life alone. SSCM offers the opportunity to treat existing comorbidities with the primary aim of improving quality of life [36]. There are approximately twenty SEDUs in the Netherlands. These SEDUs offer a stepped-up, stepped-down strategy of care to all eating disorder patients, including those in the SEED-AN [1]. However, not every SEDU offers treatment to individuals with SEED-ANs. In addition, follow-up contact in the patient's own region after the end of treatment is often suggested. For patients who live a long way from an existing eating disorder programme, this follow-up process is not always possible if a suitable solution cannot be found. In addition, the physical condition

of the SEED-AN patient also plays a role, which makes travelling to an SEDU challenging. Early findings from a recent study focusing on peer support were hopeful, and a reduction in feelings of isolation and hopelessness was observed [37]. Therefore, it seems logical to provide follow-up treatment after the end of SEDU contact through a regional outreach programme to prevent relapse and to work towards improving quality of life.

In the Netherlands, there is a separate mental health care system for people with severe mental illness (SMI). SMI is characterised by a persistent and severe mental disorder accompanied by limitations in social and societal functioning [38, 39]. A flexible assertive community treatment (FACT) approach has been developed and broadly implemented in the Netherlands [40]. In the Netherlands, one FACT team is responsible for the mental health care of an average of 200 SMI patients in a postcode area of approximately 50,000 people, focusing on goals related to physical, psychological, social and societal aspects as well as (partial) recovery and rehabilitation. FACT teams provide support in the person's own environment and social network [40]. The FACT method is a well-researched, evidence-based intervention that has been implemented in many countries [41]. FACT offers a similar philosophy, such as harm reduction approaches [42, 43], for instance, the HARMONI programme (HARm MinimalisatiON In chronic anorexia nervosa) [42]. However, a difference is the stepped-up, stepped-down philosophy as a main issue in FACT. FACT care then offers support in patients' own environment and, if needed, in patients' own home. Finally, FACT teams are composed of a variety of professionals, including psychiatrists, social workers and nurses, providing a broad range of expertise. It promotes a holistic approach where physical, psychological and social aspects remain central [44]. Given the complexity of mental health conditions and the discontinuity of care, coordinated care is indicated for persons with SEED-AN [44]. According to Delespaul (2013), persons with SEED-AN fulfil the criteria for SMI [45], and recent study findings underpin this statement [38]. Then, the (after)care for SEED-AN can be permanently improved by implementing active collaboration between the SEDU and FACT teams [18]. In practice, however, persons with SEED-AN are often excluded from FACT services because of the association between underweight and other serious health risks.

Despite the lack of exact numbers of presented SEED-AN patients benefiting from appropriate therapy in the Netherlands, it is assumed that not every SEED-AN patient receives appropriate support. This assumption is based on a small sample of the two mental health organisations involved in this research, the Parnassia Psychiatric Institute and Emergis, both located in the southwestern Netherlands. To explain this, a thorough

look was taken at the following: (1) the current therapy offered by the SEDU programmes accessible to SEED-AN patients, and (2) the presence of the DSM-5 diagnosis of eating disorders in the patient bases of the FACT teams.

In the explanation of issue (1) Scrutinising the SEDU programmes revealed the following: There is an (outpatient) clinical therapy service for SEED-AN, provided within the network by Emergis. Ten beds are available, and outpatient (follow-up) care is provided for a period of up to 2 years. The treatment offered is supraregional; potentially, every Dutch SEED-AN patient can benefit from this treatment. However, this is a difficult issue; there is often a need for structural aftercare, which cannot always be provided because of distance. Then, issue (2) The sampling was carried out in the two mental health organisations involved. The DSM-5 code was searched within the patient base of the FACT teams. For privacy reasons, patient numbers and/or other personal characteristics that could be associated with individuals were not visible. The sample from Emergis included 2 people diagnosed with AN who received care at FACT Emergis. At the Parnassia Psychiatric Institute, samples were taken from two FACT care bases (PG-FACT Haaglanden and PG-FACT Rijnmond). The sample included 22 people diagnosed with comorbid AN (private administrative data, 2021). In total, 24 people diagnosed with AN were treated by FACT teams operating in the Dutch regions of Zuid-Holland and Zeeland in 2021. It is assumed that a substantial number of SEED-AN patients are not represented in FACT care.

This study aims to systematically examine the experiences of professionals and patients regarding existing care for SEED ANs across two settings in two health districts in the Netherlands. Namely - Specialised ED Unit and FACT.

The following research question was formulated: *Can, and if so, how do FACT teams contribute to the treatment of patients suffering from SEED-AN from the perspective of professionals and SEED-AN patients?*

Its objectives were as follows:

- Create a deeper understanding of how patients with SEED-AN already perceived support from the FACT service;
- To gain a deeper understanding of the beliefs and attitudes of both FACT professionals and SEDU professionals towards SEED-AN;
- Identify the perceived barriers experienced by both FACT and SEDU professionals in approaching patients suffering from SEED-AN;

Method

This study was conducted between November 2021 and November 2023 in two participating mental health institutions in the Netherlands. Qualitative research makes it possible to give a voice to lived experiences; therefore, we conducted 22 semistructured interviews in focus groups and individually. Synthesis was then sought by combining and overlapping all sets of rich data constructed from both professional and patient respondents. Semistructured interviews were conducted and recorded by two lead researchers, a nurse practitioner and a nurse in training to become a nurse practitioner. The focus group interviews were conducted with professional respondents to discuss sensitive issues related to patients with SEED-AN in depth [46, p. 110]. Discussion was encouraged, and interaction among focus group participants broadened awareness of SEED-AN and related issues [46, p.110]. Given the vulnerability of the patient respondents, individual interviews were conducted. Rich and detailed data have been derived from the lived experiences of both patients and professionals [46, p. 80]. To closely reflect the realities, meanings, stories, interpretations and experiences of the respondents, reflexive thematic analysis (RTA) [47], which is supported by an inductive approach, was used to interpret the participants' views [46, p.174]. RTA is not used to discover the 'truth' [48], and we aimed to provide direction on the possibilities of an adapted approach for persons suffering from SEED-AN, where improving quality of life was paramount. Considering RTAs, both researchers were aware of the uncertainty that meaning was generated by the interpretation of the data and not by the amount of data excavated [49]. By mutual agreement of the researchers involved, it was decided to stop the data generation process as no longer fresh data appeared.

In RTAs, the researchers' positions, values and perspectives are integral. However, qualitative research is subjective. To ensure rigour, peer review and an independent research supervisor (for the nurse in training) and an independent researcher served as critical support [50]. We integrated several evaluation moments and used a logbook [51, p. 296]. To increase neutrality, both researchers were not involved in any of the treatments of the patients interviewed, and the researcher interviewing the professionals was not a direct colleague of the interviewees. Member checking increased reliability; respondents were presented with verbatim transcripts after the interview [52]. Transferability and authenticity were ensured by transcribing the interviews verbatim and describing the research context. Quotations from thick descriptions were used to reinforce the research findings [53, p. 505].

Sampling, recruitment and interviews

We applied purposive sampling [51, p. 190] to recruit professional respondents. The criteria:

- Professionals working in the FACT service;
- SEDU professionals.

For study participation, FACT staff and SEDU professionals were actively approached by our research team. Therefore, we used a strategy [51, p. 190]: the management of FACT and SEDU and the board of the participating institutes were invited in an online presentation to participate in the study. We highlighted the importance of improving care for SEED-AN patients and explained the study protocol. Managers were encouraged to participate in their staff for interviews. Our team contacted the FACT and SEDU practitioners personally by email or telephone to invite them to participate. We found sixteen professional respondents. Then, purposive sampling [51, p. 190] was applied in the recruitment of the patient respondents. The inclusion criteria were as follows:

- Diagnosis of anorexia nervosa, present for 5 years or intermittently present for 10 years or more;
- Patients who had received at least one usual treatment for AN (e.g., cognitive behavioural therapy enhanced (CBT-E [10]), clinical admission to a SEDU);
- Current treatment was received from a FACT professional in Parnassia.

Psychiatric Institute;

Not in mental health crisis (e.g., suicidal, psychotic).

To search for possible patient respondents, we used the business information of the Parnassia Psychiatric Institute and identified nineteen potential SEED-AN patient participants. The current therapists from the potential patient participants were then asked to test the established diagnostics to check if the diagnosis of AN was still accurate, and potential participants were then approached by their personal therapist for study participation. Thirteen candidates met the inclusion criteria. The exclusion criteria (being in crisis or incapacitated) were applied, resulting in six patients being excluded. Seven female patients agreed to participate and were interviewed. One interview was not used because the patient no longer met the criteria of SEED-AN [51, p. 184]. In conclusion, the patient sample consisted of six patient respondents.

Respondents' characteristics

To protect confidentiality, a brief description of the characteristics of both professional respondents, representing

professionals; two psychiatrists; four inpatient nurses; two clinical psychologists; three specialist psychiatric nurses; one nonverbal therapist (e.g., drama or physiotherapist); and four outpatient nurses, three male and thirteen female, is provided. It was expected that the variety of professionals was sufficient to answer the research question. All professional respondents were involved in the care of SEED-AN patients. Six professional respondents were employed in an SEDU; ten were FACT colleagues.

The characteristics of the patient respondents were as follows: all were female and aged between 26 and 65 years, with a mean age of 43 years. All patients were diagnosed with anorexia nervosa for at least 10 years and up to 52 years, with a mean duration of 27.5 years. All patients had received at least one eating disorder treatment in the past. All patients received tailor-made FACT treatment (e.g., pharmacotherapy, trauma therapy, emotional behavioral therapy, or a combination of both) for at least two years and up to thirteen years and received at least one evidence-based treatment for AN.

Data collection and analysis

Data collection took place between September 2022 and April 2023. All professional respondents were interviewed by a senior researcher, and the patient respondents were interviewed by a nurse in training to become a nurse practitioner. Within the professional group, five focus groups were formed. Three focus groups consisted of FACT professionals only, and in two focus groups, a mix of SEDU and FACT professionals was presented. Then, a nurse practitioner, a community nurse, and a nonverbal therapist, all SEDU professionals, were interviewed individually due to agenda issues. The interviews started with guided questions from a topic list [53, p. 226]. Two topic lists were developed: one for interviewing professional respondents and one for interviewing patient respondents. Both lists were drafted and reviewed by two research colleagues (see Table 1, guided questions) [54, p. 185]. The topics concerning the professional respondents were drafted from the study proposal. The topics concerning the patient respondents were based on the six quality-of-life domains formulated by the World Health Organisation: physical health, mental health, level of independence, social relationships, environment, and personal values and beliefs [55].

The interviews were then transcribed verbatim and stored in a password-protected data software program. Then, in the analysis, the six-phase structure [47, 56] was used to define and refine the data: 1.) Familiarisation; (2.) coding; (3.) generating initial themes; (4.) developing and reviewing themes; (5.) refining themes; (6.) writing up, ultimately leading to a report. In addition, a semantic approach was adopted to stay close to the data.

Table 1 Guided questions of professional and patient respondents

Guided questions professional respondents	Guided questions patient respondents
What are your experiences in the treatment of SEED-AN?	Why you think you are receiving FACT care? For what purpose?
Do you think that FACT can contribute to the treatment of SEED-AN patients?	Do you receive any support in the area of giving meaning to life and motivation? If so, how?
What do you think about the term SMI? Would the SEED-AN patient meet the SMI criteria?	what has been your experience in the treatment of your eating disorder?
Do you have an idea what kind of support is needed to treat SEED-AN patients?	Do you feel that the treatment you receive is appropriate to your problems and needs?
What kind of support would you need to treat SEED-AN patients?	What treatment options does FACT offer?
What do you think about a collaboration between the eating disorder department and FACT?	What are your expectations of your service providers?

Ethical considerations

Prior to the study, permission was obtained from the Medical Ethics Committee of the Erasmus Medical Centre in Rotterdam. Permission was also sought and granted from the institutions involved (Emergis, Parnassia Psychiatric Institute) by the Scientific Committee of Emergis and Parnassia Psychiatric Institute.

Results

Twenty-two respondents were informed about the purpose and procedure of the research, the voluntary nature of participation, the possibility of withdrawing from participation at any time during the interview, and all the respondents provided written consent for the use of their data. In total, we defined 4 themes, supported by 28 initial codes and 37 transcripts derived from rich data. The first 3 themes, A, “We feel ignorant in the treatment of SEED-AN patients”; B, “There is a disability to act,” and C, “We are more than executive practitioners alone,” focus on rich data derived from professional respondents only. Theme D, The professionals at FACT have given me back my confidence in my treatment, is based on the data from patient respondents, see Fig. 1, illustrating the organisation of the interview transcripts, into initial codes, into the final themes.

We feel ignorant in the treatment of SEED-AN patients

Across daily practice conditions, almost all the FACT professional respondents described feelings of “discouragement” in contact with other professionals when requests were made for the transfer of treatment. Some FACT professionals also experienced “distance from the SEED-AN person” and a “knowledge gap” as a result of preferring to address other mental health issues. Other FACT professionals were more active in the search for

support for mental health issues with which they were not familiar:

We have a knowledge gap. We need more eating disorder knowledge, which is also accessible to all FACT teams, and they have to make it easier to contact somebody at the SEDU, for instance, a name that is very important to us.
(Professional respondents 1 & 2-FACT)

Next, all the professional SEDU respondents struggled with feelings of “discouragement” when trying to arrange follow-up care for their SEED-AN patients within FACT. One SEDU professional respondent explicitly referred to “loitering” in the attempt to organise cooperation between the SEDU and FACT, and one SEDU respondent stated “ignorance” and “no affinity” with the target group.

Loitering! FACT is then rejected, but there is no longer a direct treatment demand for individuals with eating disorders. An outpatient setting can provide only limited care. The WMO (Social Support Act in the Netherlands) is not adequate (professional respondent 14, SEDU).

Most of the FACT professional respondents experienced feelings of “resistance” against other psychiatric illnesses other than psychosis and, for example, serious mood disorders; they were more convinced that FACT was not providing appropriate treatment for SEED-AN patients, supported by their own personal preferences.

And you also choose for a long-term care patient, mostly those with psychotic disorders. With whom you just click. Yes, and I also think that this is the mechanism by which you get further away from other client groups. (Professional respondent 5-FACT)

Analysis then established a consensus among the FACT respondents on the concept of severe mental illness (SMI); according to all SEDU and FACT respondents, SEED-AN patients met the criteria for SMI.

When I look at my client why she was accepted for our program, she was rejected from other programs, and that criterion also meets the SMI (Prof. Resp. FACT 4).

If there is more comorbidity, then it is appropriate. Yes, then it would be SMI.
(Professional respondent 3 -FACT)

THEMES	INITIAL CODES	INTERVIEW TRANSCRIPTS
<p><i>We feel ignorant in the treatment of SEED-AN patients</i></p>	<p>Loitering Distance Discouragement Resistance Knowledge gap Ignorance No affinity SMI</p>	<p>Loitering! FACT then rejects, while there is no longer a direct treatment demand in eating disorders. And an outpatient setting can only provide limited care. And WMO (Social Support Act in de Netherlands) is not adequate; We have a knowledge gap. We need more eating disorder knowledge, which is also accessible to all FACT teams, and they have to make it easier to contact somebody at the SEDU, for instance, a name; The FACT teams, which are also seen as some end-station; A psychotic person fits within our program, but other diagnoses had to be kept out a bit; And you also choose for a long-term care patient, mostly the psychotic disorders. With whom you just click. Yes, {...} that this is how you get further away from other client groups; It's a bit blunt, but a lot of colleagues say to me: I just can't stand it, if someone doesn't eat, you just must eat; So, my conclusion: ignorance and no affinity with the target group; We want to be seen as a treatment department, not a gutter; I do see the same issues within other SMI individuals; she was rejected from other programs and that criterium also meets the SMI.</p>
<p><i>There is a disability to act</i></p>	<p>Failure Knowledge gap Solo work Vulnerability Discomfort Pressure</p>	<p>And in the beginning, {...} I see progression, then, I have a bad feeling about the help offered by FACT only, and I prefer an expert on eating disorders and a GP involved. That requires cooperation and coordination, and it demands a lot from us as practical workers; I don't want to be trained anyway, because I hardly meet them (SEED-AN) in my practice; If there were more investment in psychoeducation and cooperation, and perhaps also meet the client together; I don't want to be the only one treating a SEED-AN individual, that's so vulnerable, unfortunately, I do not have a choice; You also must upskill our staff, but how do you motivate the staff to receive sufficient training? {...} Mostly, the answer is, 'I'm not going to do the training anyway, because I hardly meet them in my practice; Training focuses mainly on increasing theoretical knowledge. {...} increasing skills. You cannot learn more about an eating disorder from theory alone; But none of us all have the expertise on eating disorders.</p>
<p><i>We are more than executive practitioners alone</i></p>	<p>Lack of vision Dissatisfaction Excessive workload Pressure Financial issues Thinking in boxes</p>	<p>As a practitioner, you need your management on board by explaining why treatment for SEED-AN is important; I also ask the management to focus: How do you want to organise your care in your institution? And I think that must be done differently; I sometimes feel a bit of pressure, to conclude treatment; Financial issues and how long someone has been in care should not be in the lead; The organisation of care for SEED-AN weighs so heavily on your already full agenda. Better financial support for indirect care (coordination of care) is also needed to get treatment funded; it is so time consuming to organise follow-up care; A mental health institution should have a leader with a certain 'out of the box' vision and leads towards that vision.</p>
<p><i>The professionals at FACT have given me back my confidence in my treatment.</i></p>	<p>Flexibility Accessibility Empathy Feeling seen Discussing patterns and ED behaviour Mirroring Reason to live Severe suffering</p>	<p>If my therapist is not available, I get a substitute; And there is the social service at home, or a crisis service I could call when needed; That you realize, I don't want to die, I want to live, so I restart eating; Improving life, yeah, that is a nice goal; A purpose in life is very important; Volunteering, getting among other people. Getting started; I'm seen as a person, not as a textbook. And that is a big thing; I am treated as a human being, not as a problem; It's also that my practitioner sees through me, that there's something going on with me, while I don't know it myself; If my therapist is not available, I get a substitute. And there is a housing service or crisis service that I could call when needed; When the eating disorder started, I couldn't believe it was just a symptom of other things going on. I learned that from this team; All those 9½ years I always had the same person, which was nice; It's every day, well, you get up and all that. But it's getting through the day, and going to bed at night, and thinking, another day is over.</p>

Fig. 1 Organisation of the interview transcripts, initial codes, and final themes

Disability to act

Some FACT respondents described feelings of “discomfort” caused by the, sometimes, deplorable, physical condition of SEED-AN people, mostly related to ‘working alone’ within SEED-AN; one FACT respondent worried about the ‘vulnerability’ of their own position.

I do not want to be the only one treating a SEED-AN individual, that is so vulnerable; unfortunately, I do not have a choice. (Professional respondent 2-FACT)

One FACT respondent explicitly described the “pressure” of having to constantly coordinate and consult with multiple parties involved with the SEED-AN patient.

And in the beginning, sometimes, I see progression, then, I have a bad feeling about the help offered by FACT only, and I prefer an expert on eating disorders and a GP involved. That requires cooperation and coordination, and it demands a lot from us as practical workers. (Professional respondent 7, FACT)

However, some FACT and SEDU professional respondents explicitly reported increasing treatment skills and deepening their knowledge of SEED-AN’s approach as a method to fight against a “knowledge gap” and feelings of “failure”.

You also must upskill our staff, but how do you motivate the staff to receive sufficient training? {...} Mostly, the answer is, ‘I’m not going to do the training anyway, because I hardly meet them in my practice; training focuses mainly on increasing theoretical knowledge. However, it is also about experiential knowledge. {...} increasing skills. You cannot learn more about EDs from theory alone. (Professional respondent 5- FACT)

We are more than executive practitioners alone

All professional respondents expressed their “dissatisfaction” with the current mental health funding policy as a result of “financial decisions” made by the Dutch government and health insurers. Feelings of “pressure” and having an “excessive workload” were mentioned by almost all professional respondents.

The organisation of care for SEED-AN weighs so heavily on your already full agenda. Greater financial support for indirect care (coordination of care) is also needed to obtain treatment funding. In addition, it is time consuming to organise follow-up care. (Professional respondent 14, SEDU)

Most professional respondents also experienced discrepancies in the chosen system of categorising mental health care. For example, there is too much thinking in “boxes”. For example, for each mental health issue, a recovery pathway is developed, and professional respondents stated that these decisions are responsible for difficulties in the cooperation between care programs.

Financial issues and how long someone has been in care should not be in the lead. (Professional respondent 11, FACT)

Next, several of the SEDU and FACT professionals interviewed stated that there was a ‘lack of vision’ from management to provide treatment for SEED-AN patients.

As a practitioner, you need your management on board by explaining why treatment for SEED-AN is important. However, I also ask management to focus: How do you want to organise your care in your institution? And I think that must be done differently. (Professional respondent 11-FACT).

I also sometimes feel a bit of pressure to conclude treatment (professional respondent-15, SEDU).

The professionals at FACT have given me back my confidence in my treatment

All six patient respondents recognised “flexibility” and “accessibility” in the approach of their FACT therapists; three of them described several ways to contact their therapists, for example, by telephone, e-mail, or face-to-face. If their personal therapist was not available, it was easy to contact a temporary substitute.

If my therapist is not available, I get a substitute. In addition, there is the housing service, or crisis service, I could call them when needed. (Patient respondent 1)

All six patients described “empathy” in their therapists’ approach and experienced trust in professional relationships, which is important in long-term professional relationships, as the patient respondents stated. Four patient respondents felt “seen” by their therapist, and one acknowledged the long-term professional relationship of 9.5 years, whereas one patient respondent explicitly preferred to have three therapists available, believing that the patient was too much of a burden for one person.

When I have a hard time in my head, I can turn to three people if I need to. In addition, that is nice,

because if it is one person I feel burdened by, then I feel I'm too much for the other person. (Patient respondent III)

With respect to eating behaviour issues, none of the patient respondents would interfere with the SEDU professionals; one patient respondent refused to “discuss eating behaviour” issues; and five recognised the ambivalence concerning discussing the eating disorder. Three patient respondents mentioned the need to confront and discuss eating disorder behaviour. “Mirroring”, “discussing patterns”, or “pointing out unconscious eating behaviour” were mentioned five times.

When the eating disorder started, I could not believe it was just a symptom of other things going on. I learned that from this team (Patient respondent III).

Finally, all patients' respondents stated issues such as a “reason to live” and improving their life by increasing social contact. All the patient respondents experienced new “goals in their life”, initiated in cooperation with their FACT therapists. Some patient respondents explicitly did not want to die anymore; one patient respondent stated that life was “severe suffering”.

It is every day, well, you get up and all that. However, it is getting through the day, and going to bed at night, and thinking, another day is over. (Pat. resp. V).

That you realise, I don't want to die, I want to live, so I restart eating (Patient respondent II).

Discussion

The findings highlight how the care of SEED-AN patients is experienced in the participating mental health facilities. We used RTAs to develop themes from 22 interviews with SEDU and FACT professionals and persons suffering from SEED-AN.

Our findings resonate with previous qualitative research [18] and meet the SMI criteria [34, 38]. Interestingly, the FACT participants felt that the program met their expectations even though the providers lacked confidence. Survey research [57] ($N=628$) of patients with mental illness and substance use disorders and healthcare providers ($N=471$) highlighted stigmatisation during treatment. 52% of healthcare providers reported a focus on limitations and risk avoidance rather than opportunities and recovery, and 22% of patients reported a detached attitude from healthcare providers. The authors emphasise the importance of normalising mental health issues, which is an interesting point of view,

as our findings highlight ‘unfamiliarity with SEED-AN’, a ‘knowledge gap’, and ‘lack of affinity in working with SEED-AN’, which also resonates with previous research in the field of SEED-AN [58–60].

With these findings, we provide a deeper understanding of the beliefs and attitudes of both FACT professionals and SEDU professionals towards SEED-AN, and we identify some of the barriers experienced by the professionals involved in the SEED-AN approach.

Findings derived from health care providers highlight a wide range of policy-related issues. For example, the artificial distinction made by policymakers between the SEDU (curative) and the FACT teams (supportive), a high workload, and the request for improving financial policy and thus financial compensation for indirect patient contacts to enable consultation between the SEDU and FACT. However, the current healthcare landscape is challenging; in the Netherlands, 80,000 people are on the waiting list due to a large capacity shortage [61]. According to the Trimbos Institute (Dutch Research Institute for Mental Health), society is becoming increasingly complex; there is a structural outflow of mental health professionals of 10–15% per year, several mental health institutions are struggling to maintain their financial health, and strikingly, less attention is given to recovery, resulting in mentally ill patients remaining ‘full-time’ patients.

The findings highlight the consensus among professionals in the approach to the SEED-AN. Professionals consider SEED-AN a serious mental illness (SMI), and there is a need to address the multiple quality-of-life issues associated with SEED-AN. Our findings resonate with research comparing the Boston University psychiatric rehabilitation (BPR) approach with an active control condition (ACC) [38], the first study to include patients with a long-term eating disorder. Although not all experts agreed with the rehabilitation approach and stated a curative form, such as CBT-E, to minimise harm [62], professionals wish for better therapeutic methods where the preservation and/or improvement of the quality of life in persons living with SEED-AN should be the focus. This finding resonates with previous research conducted in the field of SEED-AN [18, 22, 58]. In our study, patients within FACT care recognised that, in their treatment, they were working towards, or had (partially) achieved, an improvement in quality of life. The patient respondents emphasised the importance of a close working relationship with the professional in which they wanted to be seen, known and recognised. This stated importance and desire for a therapeutic alliance within anorexia nervosa treatment has also been found in previous research [63, 64] and emphasises the importance of (restoring) epistemic trust within the therapeutic relationship, which refers to the ability to learn from new experiences on the basis of confidence that the knowledge gained is relevant,

reliable and applicable [64]. The desire and motivation to ‘fight the eating disorder’ seemed ambivalent in our study and variable in strength, which is in line with studies on SSCM [18, 32]. Perseverance was not constant, and the perceived level of suffering was high. To increase the therapeutic alliance among SEED-AN patients, Jochems [65] argued that by supporting the three basic psychological needs of autonomy, competence and relatedness, patients were better able to sustain the treatment process and engage in behavioural change, leading to better treatment outcomes [65]. Patient respondents expect professionals to confront, reflect and question them about food and weight, but taking the initiative to discuss these issues themselves is sometimes perceived as too difficult. It is therefore important that agreements about focus, goals, working methods and expectations are made before treatment begins [66]. All respondents value integrated care and collaboration with other healthcare providers, including those in the social sector. This requires good coordination and communication within health care networks [67]. FACT focuses on finding support within one’s own network. With respect to patient respondents’ outcomes, an adjustable model could benefit the cooperation of parties involved in the support of the patient. For example, the use of the resource group model. This model is ideal for realising collaboration between different parties, e.g., patients, FACTs, SEDUs, families and other important people [68], and shows similarities with the recovery-oriented approach [69]. The resource group model is a further development of assertive community treatment (ACT), created in the year 2000. A resource group is a group of people chosen by patients, consisting of professionals and nonprofessionals, who help achieve self-selected recovery goals [70]. Furthermore, using the resource group model, caregivers (e.g., SEDU and FACT professionals, family members) could easily exchange psychoeducation to receive a higher level of knowledge to support patient needs. We offer the model as a possible solution for the expressed needs of FACT and SEDU professionals for integrating each expertise and combining strengths to optimise SEED-AN treatment. The composition of the resource group, which is chosen by the patient and who can provide support, may have a positive impact on recovery and adherence to treatment, reducing the need for care and the risk of relapse [70]. An advantage of the resource group model is the steady implementation of the model in the Netherlands [71]. Further research in the field of SEED-AN that implements the resource group model is highly recommended.

Conclusion

The findings highlight the impact of discouragement, the knowledge gap, the vulnerability of working solo within SEED-AN patients, and sometimes poor working

conditions, as stated by the professional respondents, versus the experience of a close and long-term working relationship with their FACT therapists, as reported by SEED-AN patients. Our findings support the need for collaboration between patients, other key stakeholders, and various professionals to improve quality of life. The use of a resource model provides tools to improve this collaboration, and we highly recommend further research on the implementation of a resource group model in the care of patients suffering from SEED-AN.

Limitations

In autumn 2020, a request was formulated to improve the treatment offered to patients suffering from SEED-AN. Although the study started vigorously, it slowed down during the COVID-19 pandemic. A staff shortage effectively reduced the availability of the research group. However, these obstacles did not affect the trustworthiness or validity of the results. The results were critically discussed and presented in an interim presentation (on paper and online). To obtain sufficient data, it was then decided to conduct individual interviews with professionals in addition to focus groups. With respect to the nurse in training, the training status requires that a nurse in training conducts research within his or her own mental health facility. Therefore, to achieve an average ‘cross-sectional sample’, a broad recruitment search was conducted within the Parnassia Psychiatric Institute only.

Abbreviations

SEED-AN	Severe and enduring eating disorders – Anorexia nervosa
AN	Anorexia nervosa
SEDU	Specialised eating disorder unit
FACT	Flexible assertive community treatment
PG	Parnassia groep
SMI	Severe mental illness
RTA	Reflexive thematic analysis
WMO	Wet Maatschappelijke Ondersteuning (Social Support Act)
BPR	Boston University psychiatric rehabilitation
ACC	Active control condition

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Declarations

Consent for publication

All authors have given their consent for publication of this manuscript.

Competing interests

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