Psychiatr. Pol. 2020; 54(4): 821–833
PL ISSN 0033-2674 (PRINT), ISSN 2391-5854 (ONLINE)
www.psychiatriapolska.pl
DOI: https://doi.org/10.12740/PP/OnlineFirst/118601

Chronic anorexia nervosa: Patient characteristics and treatment approaches

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Summary

Anorexia nervosa constitutes a major challenge to medical practitioners, especially clinicians, due to a high rate of chronicity and a very serious risk of relapse. One of the underlying causes of this state of affairs is the ego-syntonicity of the disorder, which differentiates it from similar conditions, and which is responsible for the patient's denial and lack of motivation for treatment (resulting in frequent instances of therapy refusal or drop-out). The paper outlines different approaches to defining chronic anorexia nervosa. This form of anorexia and its therapeutic implications are discussed through the lens of clinicians and other medical professionals. Furthermore, the patients' experiences of chronic anorexia nervosa are described. The dilemmas concerning palliative care for this group of patients are addressed and treatment options and relapse prevention strategies are recommended, with a focus on the latest developments in this respect. The paper is concluded with an optimistic report of complete recovery from this diagnosis, including an analysis of the factors underlying the positive therapeutic outcome.

Key words: chronic anorexia nervosa, motivation, psychotherapy

Introduction

This article has been based on the analysis of 52 articles, 23 of which came from the author's own collection and 29 texts from the NCBI portal. The database was searched using the following key words: chronic, enduring anorexia nervosa. Even though the initial search found 130 articles, 101 of them were removed as their topics exceeded the scope of this article (biological or radical feminist approach, methodology, therapeutic relationship, quality of life, case study, diseases other than eating disorders).

Defining chronic anorexia nervosa

Anorexia nervosa (AN) is particularly challenging to treat due to a high degree of chronicity and a significant risk of relapses [1]. According to Bulik [2], only half of patients with anorexia nervosa fully recover (taking into account the period of 21 years since the onset), in the other half it either becomes chronic or leads to death. Furthermore, Treasure et al. [3] suggest that more than 50% of patients with AN develop a severe and enduring form of the disorder, while Borson and Katon [4] indicate that despite the social stereotype that AN is an acute illness with a dramatic course affecting young women, 30% to 50% of individuals with AN experience a relapse.

Bauwens et al. [5] observed that even though most patients with AN face a long therapeutic trajectory that does not necessarily end in a positive outcome, a consensus as to the definition of chronic and/or refractory (treatment-resistant) AN has not been reached. In approx. 20% of patients with AN, the disorder develops a chronic course, remaining unresolved for 10 years or more [6], yet sometimes the shorter duration of the illness, e.g., more than 3 years, is considered as an indication that it has become chronic [7]. In general, apart from long duration, the criteria necessary for the chronic AN diagnosis include the persistence of symptoms and failures of successful treatment [8].

Surprising results were reported by Wildes et al. [9], who examined 355 patients with AN upon hospital admission and discharge in an effort to develop a definition of severe and enduring anorexia nervosa (SE-AN). Structural equation mixture modeling was verified empirically to study if the presence of potential SE-AN indicators (duration of the illness, history of treatment, BMI, binge-eating and purging episodes, quality of life) can be grounds to create subgroups of patients (including an SE-AN one). The best fit to the data was identified for a three-factor, two-profile mixture model. The first factor encompassed eating disorder behaviors, the second one included quality of life, and the third one consisted of illness duration, number of hospitalizations and admission BMI. The profiles differed in terms of eating disorder behaviors and quality of life, but not in terms of chronicity or BMI. In other words, no evidence was found for the existence of a distinct SE-AN subgroup. Given that existing SE-AN definitions are based on illness duration, this finding has important ramifications for research and clinical practice.

Patients with chronic AN from the clinical perspective – therapeutic implications

According to Bauwens et al. [5], multiple therapies failing in a single patient are often quite correctly interpreted by clinicians as evidence of complete treatment resistance. Indeed, no experienced clinician would expect patients with AN to eagerly

embrace a treatment course as such individuals have already ignored warnings from physicians, family and friends concerning the adverse consequences of malnutrition and cachexia. AN is deemed extremely difficult to treat as the disorder seems to be 'desired' by the patients, who deliberately induce its symptoms, in contrast to most other illnesses. Recovery is feared due to anticipated suffering caused by a failure to adhere to a strict dieting or exercise regimen. The relationship between therapists and patients with chronic AN is unlike that found in other patient groups. The treatment of individuals who are so vehemently opposed to change may indeed appear paradoxical, especially that the prospects for a full recovery diminish with illness duration [10–13].

In the case of patients with chronic AN, treatment cannot be 'forced' and the therapist should accept the prospect of a tedious psychotherapeutic process [14]. The planning of the patient-therapist relationship requires a fundamentally different approach, within which therapists must expect little and formulate goals cautiously. Given that the factors maintaining the disorder provide a sense of safety to the patients, any efforts aimed at depriving them of dieting rituals would be tantamount to a demand that they 'blindly' embark on what they perceive as a perilous journey into desires and instincts, however well-meaning, thoughtful, and empathetic the therapist may be [14].

Patients with chronic AN treat their disorder as a 'friend' that gives them psychological comfort and this is why interventions that are deemed ethical, moral and clinically correct by the therapist may unsettle them and push them further into defiance and refusal to eat. Thus, the therapist should define simple goals, with an approach characterized by warmth, caution, and mitigation of suffering. In this modified approach, symptom alleviation will necessarily be very modest, which does not mean that such interventions are easy-to-implement [14].

Without doubt, work with individuals affected by chronic AN can hardly be rewarding for the therapists, who may be disheartened by the routine in the patients' life and experience a sense of burnout, or at best wasted time, when faced with unrelenting resistance to change. The dialog with such patients is typically so tedious that it would not be advisable to see several of them within one day, and a failure to use supervision would be unwise. The treatment of such severely ill individuals may appear hopeless and tiring, with their petty complaints looming as 'mountains of burden' and the desire to be free of the patient, according to Strober [14], "rippling scarcely beneath the skin". It is crucial that the therapists be capable of accepting monotony while exhibiting deep compassion for human suffering. They should be able to confront crises without despondency or anxiety (even though such feelings often arise during therapy), remaining mindful in the face of "a life that flirts with death." Last but not least, they must be ready to engage in a deep, honest and thoughtful dialog about the sadness of a life that is not fully lived. Exposing the patient to painful reflections is risky, and so it should be done very cautiously, at a time that is intuitively deemed

right by the therapist. Only then can such a dialog bring a measure of relief to either party. Furthermore, the therapists should be aware of the kinds of emotions likely to be experienced by patients, possibly providing some clues as to the interventions that may be accepted by the latter.

The management of patients with chronic AN forms a separate field within eating disorder research. Such therapy presents a formidable challenge and difficulty that requires of the therapists a high degree of tolerance, authenticity and professionalism, which should translate not only into progress in therapy, but also into respect for the patient's individuality, the ability to understand sensitivity and profound suffering, accompanied by the readiness to explore deprivations and wounds. The therapists should also appear at ease to the patient. The objectives of therapy are generally quite limited by the nature of chronic AN. The management of this disorder centers on working with the patient's sensitivity while accepting the difficulty of making therapeutic progress [14].

Patients with chronic AN and medical personnel

It is crucial that patients with severe and enduring AN be treated by an interdisciplinary team composed of highly experienced specialists [15]. It is worth finding out the opinion of staff members on the treatment of this form of AN. Tierney and Fox [16] conducted a study to elucidate the views of health professionals on specific issues related to the therapy of patients with chronic AN. The study consisted of three rounds: in the first round, the authors used an open-ended questionnaire concerning AN and its treatment, which was e-mailed to 23 professionals: eight nurses, seven psychologists, four dietitians, three doctors, and one occupational therapist. In the second round, using the answers from the previous round, the same specialists were sent statements (11 statements concerning a definition of chronic AN and 24 statements about an optimal course of treatment) to be evaluated on a Likert scale (from 1 – strongly disagree to 7 – strongly agree. Completed questionnaires were returned by 21 respondents. In the third round, a shortened version of the questionnaire, containing those items which had been rated 6 or 7 by more than half of the respondents in the second round, was distributed among 68 delegates at a conference devoted to chronic AN held by the BEAT (Beating Eating Disorders) – organization that is a part of Eating Disorders Association – with 32 questionnaires returned. The respondents reached a consensus on such aspects of AN as weight, behavior (e.g., food restriction), ego-syntonicity, and cognitive functioning, while there was no clear agreement as to hormonal disturbances, social functioning and illness duration required for a diagnosis of chronic AN. Interestingly, some respondents used the criterion of (a lack of) motivation for treatment rather than illness duration. The respondents also disagreed as to the number of treatment attempts that would point to an enduring disorder; some indicated that treatment may

last many years or that multiple therapeutic attempts may be undertaken over a short period of time; moreover some patients may remain undiagnosed for years, and thus not receive treatment.

Patients with chronic AN and palliative care

A major challenge to the medical personnel dealing with anorexic patients is the perception that little can be done beyond alleviating the medical consequences of AN and providing palliative care [17]. It is worth to mention the notion of palliative psychiatry. Palliative psychiatry is an approach that improves the quality of life of patients and their families in facing the problems associated with life-threatening persistent mental illness through the prevention and relief of suffering by means of a timely assessment and treatment of associated physical, mental, social, and spiritual aspects [18–20]. According to Westmoreland and Mehler [17], many patients with severe and enduring eating disorders (SEED) are characterized by a cyclic pattern of weight gain and loss. Also many of them question the utility of treatment, especially when they experience few (if any) periods of remission. Patients with SEED may contemplate whether death resulting from compassion-motivated discontinuation of treatment would be preferable to continued suffering throughout almost their entire lifetimes. Under the circumstances, the patients, their families and doctors tend to focus on the lessening of the medical complications of the disorder and palliative care. Bauwens et al. [5] suggested that when the involuntary treatment of patients is unsuccessful, the medical personnel should limit their interventions to supportive and palliative care as an alternative to standard active measures in chronic and refractory anorexia nervosa. In this case, medical care should aim at providing psychological comfort and better quality of life [21–25]**.** Similarly, Lopez et al. [26] proposed that palliative care could be offered to alleviate long-standing suffering in patients whose physical and mental state deteriorates despite treatment. At this point palliative care in a hospice may be a humanitarian alternative to active therapy.

However, is palliative care the only solution when the medical personnel is confronted with chronic and refractory AN? According to Williams et al. [15], doctors dealing with chronic disorders (including enduring AN) should demonstrate tolerance to stress and an ability to overcome negativity, as only then will they be able to provide support and effective treatment to the patient who, over a period of many years, may need continuous care provided by therapists demonstrating an unfaltering positive attitude. The authors [15] claim that one should prevent situations in which the patients' physical and emotional health deteriorates to a point where they, their families and their doctors deem the cessation of active treatment and death as the only acceptable option. According to these authors, the pessimism of the patients and their relatives at

a time of illness exacerbation should not preclude active measures, as compassionate decisions may sometimes hinder the provision of adequate care.

What do patients with chronic AN feel?

Fox and Diab [27] conducted a study involving six patients with chronic AN (mean age – 27 years, mean illness duration – 7 years) who were interviewed using the following set of questions: Can you tell me about how you developed anorexia? For what reasons do you think that anorexia has continued to be prevalent in your life? What have your experiences of treatment/therapy been like? How do you think professionals view anorexia? What have your relationships been like with other people with anorexia? How do you see your life in the future? An interpretative phenomenological analysis of the responses revealed the following five themes: making sense of AN, experience of treatment/therapy, interpersonal relationships, battling AN, and staff pessimism in the treatment of AN. The results showed an extremely strong relationship between the identity of the patient and his/her illness and how difficult it is for him/her to fathom life without it. The study also reported that patients with enduring AN defined their identity through the lens of their disorder. They tended to perceive the medical personnel as allies in fighting the illness, but unfortunately they often believed that those persons did not have sufficient knowledge about AN, which made them pessimistic and hopeless when offering help [24, 28].

Preventing relapses in the process of treating patients with chronic AN

Treasure et al. [3] reported a 39% remission rate for females versus 59% for males after five years of illness duration. Thus, relapses are indeed a pervasive problem in this group of patients.

Mander et al. [1] studied the relationship between the stages of behavior change as proposed by Prochaska and DiClemente[1] (Transtheoretical Model of Change, TMC) [29, 30] and treatment outcomes with a focus on relapse prevention in patients with chronic AN in the maintenance stage. In the next step, the authors investigated the stages of change in the context of the therapeutic alliance. To measure relapse prevention in the maintenance stage, 39 patients with chronic AN (at early, middle,

[1] These stages include: precontemplation – the patient undergoes therapy but does not think he/she has a problem or is not sure whether he/she wants to change; contemplation stage – the patient begins to be aware of his/her problem or notices some worrying symptoms; preparation – the individual feels that he/she is ready for change and willing to bear the costs that it may entail, but he/she has not yet started to work with his/her problem (with a view to changing his/her behavior or environment); action – the patient undertakes an active change of himself/herself or his/her environment, but he/she needs help as he/she is not yet very efficacious in that regard; maintenance – the patient has changed, but he/she finds it difficult to sustain the change, and so he/she seeks help to prevent relapse.

and late phases of inpatient therapy) were asked to complete the University of Rhode Island Change Assessment-Short (URICA-S) questionnaire. General psychopathology was assessed with the Symptom Checklist-90-R (SCL-90-R) and the weight of the patients was determined. The risk of relapse operationalized using the URICA-S symptom maintenance scale was a significant predictor of general psychopathology, while BMI did not predict the stage of change. It was found that indeed the URICA-S maintenance scale can be reliably used for estimating the risk of relapse. High scores on this scale may be regarded as one of the important aspects that may be implemented as an element of post-treatment relapse prevention programs.

Treatment of patients with chronic AN

Long et al. [31] noted that even though a long-term follow-up study of AN showed an almost 50% rate of full recovery, there is a scarcity of controlled trials concerning the psychotherapy of these patients. Patients with chronic or severe AN constitute a major challenge to the therapists.

Hay et al. [32] claim that the treatment of chronic AN could potentially benefit from cognitive behavioral therapy (CBT), cognitive remediation therapy with emotion skills training, the Maudsley model family-based therapy, the community outreach partnership program, specialist supportive clinical management, as well as Strober's approach focused on therapeutic alliance and flexible goals.

Most reports on the effectiveness of treatment of persons with chronic AN involves the cognitive behavioral therapy [33] and its greater effectiveness compared to the specialist supportive clinical management [34–36]; however, in the case of the purging subtype of the disorder, the prognosed outcomes are worse. One study did not confirm the positive contribution of CBT to the improvement of the condition of chronic AN patients [37]. Positive results of case management in the treatment of chronic AN have been demonstrated [38].

Paradox-based therapy [39] and bright light therapy [40] yield good results in the case of chronic AN. Moreover, the effectiveness of support groups in the treatment of this disorder has been confirmed [41]. It is also worth mentioning that the effectiveness of using Dronabinol – synthetic tetrahydrocannabinol – has been confirmed [42]. There are also reports concerning the treatment of chronic AN with an opiate receptor blocker in combination with parenteral nutrition [43] within an auto-addiction paradigm [44], but with inconclusive outcomes. Researchers also point out potentially positive results of using olanzapine [45].

Strober [46] indicates the need for a unique approach to minimize the risk of iatrogenic effects of rapid weight gain and the negative impact of poorly worked-through countertransference.

Patients with chronic AN are highly appreciative of treatments involving collaborative and normalizing approaches, supportive contact with other patients, as well as experienced and understanding clinicians in contrast to involuntary or atypical treatments, competitive contact with other patients, and inexperienced or disinterested clinicians [6].

An interesting catalogue of treatment approaches to severe and enduring AN was proposed by Treasure et al. [3], who observed that the overarching goal of therapy should be to change the factors maintaining the disorder.

The authors mentioned:

- in terms of cognitive functioning interventions – cognitive remediation therapy (CRT), which is akin to a 'laboratory' for patients with AN in which they can actively discover new, more helpful thinking strategies. CRT includes a variety of tasks and activities aimed at developing cognitive flexibility and holistic information processing [47];
- in terms of interventions targeted at emotional difficulties – short video clips showing pleasant images and texts accompanied by relaxing music used to induce a positive mood and increase the patients' motivation for work towards recovery;
- in terms of interventions targeted at social difficulties – cognitive bias modification (CBM) training based on the 'dot probe' task. Initially, a probe is presented centrally onscreen, followed by a simultaneous appearance of two stimuli: an emotionally valenced one and a neutral one. These can be words or images positioned left and right or up and down on the screen. Immediately after their disappearance, a probe is displayed in place of one of them. The participants react to the probe by pressing a corresponding computer key indicating its position (up, down, left, or right) as fast and as accurately as possible. A version of the task used for the modification of cognitive bias is similar, but the location of the target stimuli is manipulated so that their relative proportion is higher at a given position depending on the goal of the training. For instance, in order to induce and train the bias of turning attention away from threat and towards neutral stimuli, the target stimuli are displayed more often in the neutral rather than threatening stimulus position. This is done on the assumption that tens or hundreds of trials inducing this attention bias would help the participant turn attention towards areas free of the threats. This method is more and more often used in patients with eating disorders, in their case the most often used is the training of distraction from threatening stimuli related to food, body shape, or weight;
- in terms of biological interventions – neuromodulation approaches including deep brain stimulation, transcranial magnetic stimulation and transcranial direct current stimulation were found to be non-destructive, patient-adjustable and reversible (in terms of consequences) methods of modifying the brain circuitry. In the case of individuals with eating disorderes, neuromodulation has been applied to circuits

linked to the reward system, mood regulation, and inhibition. Such impacts are often combined using multimodal neural imaging [48]. Researchers into the so-called neuroethics [34] emphasize that such impacts are more morally justified than brain surgeries (cf. the term 'neuroethics' [49]);

- in terms of pharmacology – recent years have seen extensive research into the role of oxytocin in AN treatment as the significance of that hormone in social processes has been repeatedly demonstrated. It has been shown that oxytocin promotes trust, facilitates social emotional communication and reduces the negative interpretation bias and attention bias towards negative emotions and food – and body image-related stimuli.

Recapitulation – new hope in treating chronic AN

Despite the fact that chronic AN is extremely difficult to treat, recovery is not impossible. Dawson et al. [50] interviewed eight women who recounted their stories of resolution of enduring AN. Qualitative narration analysis showed that in such cases the recovery process is long and complicated and involves four phases ranging from a state of being unable or unready to change, through reaching a tipping point, to an active pursuit of recovery and rehabilitation combined with reflection. It was demonstrated that a complete resolution of chronic AN is possible, with the crucial factors being hope, motivation, self-efficacy, and support from others. According to the transtheoretical model of change [29, 30], motivation-based interventions used in AN treatments involve a decisional balance model (considering arguments for and against change), with a lesser focus on the feelings of hopelessness and helplessness. However, in this group of patients it is hopelessness, a sense of inefficacy and low self-esteem that appear to be the main obstacles to recovery. In patients who have been suffering from AN for years and have gone through multiple failed therapeutic attempts, interventions enhancing hope for a positive resolution could increase the likelihood of improvement. Hope and self-efficacy may be improved by exchange of information between those who have recovered and those who are still suffering from AN. The results of one study [51] also emphasize the role of an internal locus of control (cf. self-determination theory, SDT), in the sense that change is possible when the individual appreciates the personal importance of an activity.

The described study has revealed a number of factors that help the patients internalize the value of change, which leads to self-determined recovery efforts. These factors include: devaluation and externalization of the disorder, improved insight, and a sense of being better understood and connected to others. Thus, treatment should include these factors, as well as those associated with interpersonal relations (with both healthcare professionals and family). These factors seem to be embodied in the new approach

to the treatment of anorexia nervosa in adults recently developed by Maudsley [52], which involves intrapersonal work, work with significant others, the development of identity beyond AN, questioning the value of AN, as well as the externalization of AN.

Acknowledgments: this research project was supported by a grant for maintaining research potential awarded by the Cardinal Stefan Wyszynski University in Warsaw, No. PBF-23/17

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