Chapter

Patients' and Carers' Perspectives of Psychopharmacological Interventions Targeting Anorexia Nervosa Symptoms

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Abstract

In clinical practice, patients with anorexia nervosa (AN), their carers and clinicians often disagree about psychopharmacological treatment. We developed two corresponding questionnaires to survey the perspectives of patients with AN and their carers on psychopharmacological treatment. These questionnaires were distributed to 36 patients and 37 carers as a quality improvement project on a specialist unit for eating disorders at the South London and Maudsley NHS Foundation Trust. Although most patients did not believe that medication could help with AN, the majority thought that medication for AN should help with anxiety (61.1%), concentration (52.8%), sleep problems (52.8%) and anorexic thoughts (55.6%). Most of the carers shared the view that drug treatment for AN should help with anxiety (54%) and anorexic thoughts (64.8%). Most patients had concerns about potential weight gain, increased appetite, changes in body shape and metabolism during psychopharmacological treatment. By contrast, the majority of carers were not concerned about these specific side effects. Some of the concerns expressed by the patients seem to be AN-related. However, their desire for help with anxiety and anorexic thoughts, which is shared by their carers, should be taken seriously by clinicians when choosing a medication or planning psychopharmacological studies.

Keywords: anorexia nervosa, psychopharmacological treatment, treatment effects, side effects, opinion survey, patients, carers

1. Introduction

1.1 Anorexia nervosa

Anorexia nervosa (AN) is an eating disorder. According to the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) [1], its diagnostic criteria are significantly low body weight, intense fear of weight gain, and disturbed body perception. The prevalence of AN is up to 1% among women with a men-to-women ratio of 1–10 [2]. The peak incidence is at an age between 14 and 17 years [3]. The course is often chronic, and it can lead to persistent disability [4]. A recent

longitudinal cohort study showed that only about 30% of patients with AN have recovered after 9 years [5]. AN has also been reported to be associated with a significantly increased mortality with a standardized mortality ratio (SMR) of 5.21 [6]. Thus, novel approaches such as psychopharmacological options should be considered to improve the treatment outcome and the care for people with AN.

1.2 Carers' help for patients with anorexia nervosa

Family members, partners and friends are usually highly motivated to care for patients with AN, but they are also often suffering. AN can make them feel guilty or anxious which is neither justified nor helpful. Family therapy for AN can tackle these feelings, can identify interpersonal difficulties maintaining the disorder, teach psychosocial and communication skills, and thus enable the carers to help the patients work towards recovery [7, 8]. The carers' help may also include supporting psychopharmacological treatment.

1.3 Psychopharmacological treatment for anorexia nervosa

The discovery of psychopharmacological treatment options in the 1950s led to a massive breakthrough in the treatment of schizophrenia and depression. Patients who previously had to live in asylums became enabled to lead a self-determined and autonomous life with their families, and resume taking up employment [9]. Patients with AN, however, did not benefit from this success, as the antipsychotics and antidepressants developed did not prove to be effective in AN.

Psychiatric researchers have unsuccessfully tried for decades to apply these medications to the treatment of AN, which is why there is no single medication approved for use in AN [10]. Part of the problem is the difficulty in conducting randomized controlled trials (RCTs) in AN. Most of these RCTs chose weight gain as their main outcome criterion. However, this is what patients with AN fear, and this fear is indeed a symptom of their disorder. Therefore, recruitment for psychopharmacological studies in AN has been a significant challenge [11]. Despite these obstacles, RCTs have been performed and published, although the recruitment rate of these RCTs has been so low that the results may not be generalizable.

The lack of effective psychopharmacological treatment has left patients with AN in a situation where clinical treatment outcomes are very modest. End-of-treatment remission rates of RCTs in adult patients with AN range between 13 and 43% [12]. This is a sobering figure highlighting the pernicious nature of AN and its mortality rate, which is—as already mentioned above—five to six times greater than in the general population [6, 13, 14].

The biological mechanisms leading to AN are not completely understood. Therefore, currently it is not possible to design a drug that would specifically target the biological cause of this psychiatric disorder [10]. However, clinicians could consider prescribing medication that targets certain symptoms which are important or frequent in patients with AN.

1.4 The patients' perspective

During the psychiatric history taking and examination, patients with AN often report that they use self-starvation to cope with stress, difficulties and overwhelming emotions. Thus, AN could be seen as a strategy for coping with underlying problems such as stress, anxiety or low mood [15]. Therefore, a medication that induces appetite and increases weight could be perceived by patients with AN as a way of re-exposing them to these underlying problems. Therefore, when drug

treatment is considered, patients with AN are more interested in whether this medication might help with certain psychological symptoms including anxiety, mood, and problems with concentration and sleep [10, 16].

Weight gain can thus only be a first treatment step to reverse the acute effects of starvation. Relying on weight outcomes alone in drawing conclusions from RCTs could inflate the interpretation of positive results [14]. Instead, weight gain and psychological improvement should be considered as important treatment outcomes in their own right [14].

Psychopharmacological agents have potential side effects, including an increase in appetite, weight gain, binge eating, alterations in metabolism, cardiac problems, nausea, haematological changes, tiredness, mood changes and other psychological effects. It is important to share these potential side effects with the patients when obtaining their consent to treatment, as sharing this knowledge helps the process of shared decision-making about a psychopharmacological treatment and contributes to drug safety [17, 18].

1.5 The carers' perspective

As carers can support their loved ones towards recovery [19], it makes sense to involve them in medical and specifically psychopharmacological decisions. They can support patients when they take their medication, and they can observe and report beneficial and adverse effects. Thus, we surveyed the carers' views and expectations towards psychopharmacological treatment for AN. In this chapter, the term 'carer' is used quite broadly. It can be anyone caring for a person with an eating disorder, such as a parent, a sibling, a partner or a friend.

1.6 Aim of this study

This study was performed to survey the patients' and carers' perspectives of psychopharmacological interventions targeting symptoms of AN. Therefore, a questionnaire was developed to gather the patients' views and another questionnaire, with questions of similar content, was developed to gather the carers' views. In this book chapter, we present both these questionnaires on the patients' and the carers' views on psychopharmacological treatment for AN, and we report on the statistical results of the survey.

2. Methods

2.1 Development of the questionnaires

In order to perform a quality improvement (QI) project in the Eating Disorders Service of the South London and Maudsley NHS Foundation Trust (SLaM), we developed a questionnaire for such a project. The QI project team consisted of patients and psychiatrists from the eating disorders inpatient ward, the 'step-up' service (a day-hospital service) and the outpatient unit of SLaM. The questionnaire has three main sections. The first section provides basic information on the patient or the carer and their experience with medication prescribed to them or their loved one respectively. The second section asks about what therapeutic effects a psychopharmacological medication should have to help with symptoms of AN. The third section is about concerns of potential side effects.

Initially, the questionnaires were distributed to a group of 17 patients with AN and 16 carers between June 2016 and January 2017. The answers given were

evaluated and the main results have been published in a scientific letter [16]. The feedback received from SLaM patients, carers and colleagues suggested minor alterations to the wording of a few questions and the addition of three further questions. Therefore, we made these changes accordingly and distributed the questionnaires to a second cohort of 19 patients and 21 carers between March and September 2018. Thus, taking both cohorts together, we obtained completed questionnaires from 36 patients and 37 carers.

The patient and the carer questionnaires used in the second cohort are depicted in the appendix of this article.

2.2 Study sample

The total sample of people who completed the questionnaires included 36 patients and 37 carers.

Patients were all females between 18 and 44 years of age; mean age: 27.64 years ± 6.85 standard deviation (SD); seven were treated as outpatients, five as day-patients and 24 as inpatients in our specialist unit at the time of the survey. The duration of treatment ranged between 1 week and 15 years; mean duration of treatment: 50.12 weeks ± 136.62 SD. The duration of their AN was between 1 year and 24 years; mean 9.03 years ± 6.67 SD. Twenty-four of these patients were currently receiving psychopharmacological treatment.

The carers were 21 males and 16 females between 21 and 71 years; mean age: 51.40 years ± 11.11 SD. Their close others with AN were two male and 35 female patients between 18 and 44 years old, mean age: 24.62 years ± 6.71 SD. Of these close others with AN, 12 were treated as outpatients, three as day-patients and 22 as inpatients in our unit at the time of the survey. The duration of treatment of these patients ranged from 'not yet started' to 52 weeks; mean duration of treatment: 11.60 weeks ± 12.20 SD. The duration of their AN was between 1 and 20 years; mean 7.01 years ± 6.64 SD. A total of 27 of these patients were currently on medication for mental health problems.

2.3 Data evaluation and statistics

The questionnaires were statistically evaluated using IBM SPSS statistics version 24. We used descriptive statistics to evaluate the questionnaires.

For consistency, the additional questions in the new version of both the patients' and the carers' questionnaires were excluded from statistical evaluation. Thus, the questions on appetite increase and improved gastrointestinal symptoms as potentially desired effects of medication for AN were not included, nor was the question about concerns of changes in the way of thinking as a potential side effect. The evaluation of free text answers was not part of the current publication.

3. Results

3.1 Opinions about therapeutic effects of a medication for anorexia nervosa

Regarding the overall opinion on drug treatment for AN, most patients disagreed in our survey with the view that medication could help with AN, whereas the majority of carers were undecided in this regard. Approximately one third of patients were also neutral about this. In terms of the question on whether patients with AN should consider medication for treatment, a proportion of almost 40% of patients and carers expressed no particular point of view. However, more than half

of the carers believed that patients with AN should consider drug treatment. Most of the patients agreed or strongly agreed with the statement that they did not want medication for treatment with AN, whereas the carers had more diverse opinions in this respect with ~40% of neutral opinion and 65% of carers believing that medication should be taken if recommended. However, patients were more cautious about this statement, with 42% expressing a neutral view on this.

The results revealed that ~50% of patients agreed or strongly agreed with each of the following target symptoms of psychopharmacological treatment: anxiety (61.1%; sum of 'agreed' plus 'strongly agreed'), concentration (52.8%), sleep problems (52.8%) and anorexic thoughts (55.6%). Most of the carers shared the view that drug treatment should help with anxiety (54%) and anorexic thoughts (64.8%).

In both patients and carers, ~75% stated that more research on drug treatment for AN is needed. As much as 40% of patients expressed their willingness to take part in such research, and ~25% of patients were undecided about whether they should take part or not.

Detailed information on the frequencies and percentages of answers concerning the therapeutic effects of a medication for the treatment of AN can be found in **Table 1**.

3.2 Concerns about side effects of medication for anorexia nervosa

More than 90% of patients agreed or strongly agreed that they had concerns about potential weight gain during psychopharmacological treatment, and about the same number of patients also expressed concerns about appetite increase during drug treatment. Furthermore, the majority of patients were afraid of binge eating, changes in body shape and changes in metabolism.

Most of the patients were also concerned about potential side effects not related to appetite or weight regulation. These included changes in mood, tiredness or sleepiness, problems with the heart or the heart rhythm, nausea, decreased concentration, changes in laboratory parameters and sleep problems.

By contrast, a majority of carers were not concerned about weight gain, appetite increase, and changes in body shape nor metabolism. However, most of the carers feared binge eating as a side effect and adverse effects related to mood, tiredness, heart problems, nausea, concentration, laboratory parameters and sleep.

Detailed information on frequencies and percentages of answers concerning the potential side effects of a medication for the treatment of AN can be found in **Table 2**.

4. Discussion

4.1 Summary of findings

Taken together, we have developed questionnaires for patients with AN and for carers to express their opinion on psychopharmacological treatment for AN. Most patients did not think that medication could help with AN. However, the majority of patients thought that medication for AN should help with anxiety, concentration, sleep problems and anorexic thoughts. In this respect, most of the carers shared the view that drug treatment for AN should help with anxiety and anorexic thoughts. Almost all patients who participated in the survey had concerns about potential weight gain and increased appetite during psychopharmacological treatment, and most of them also feared changes in body shape and metabolism. The majority of

	Patients (N = 36)		Carers (N = 37)	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**
Medication could help with anorexia nervosa				
Strongly disagree	1	2.8	0	0
Disagree	18	50.0	1	2.7
Neutral	11	30.6	21	56.8
Agree	6	16.7	12	32.4
Strongly agree	0	0	2	5.4
Patients with anorexia nervosa should consider medication for treatment				
Strongly disagree	3	8.3	0	0
Disagree	5	13.9	1	2.7
Neutral	14	38.9	14	37.8
Agree	12	33.3	20	54.1
Strongly agree	2	5.6	1	2.7
I do not want medication for anorexia nervosa				
Strongly disagree	2	5.6	7	18.9
Disagree	8	22.2	8	21.6
Neutral	7	19.4	14	37.8
Agree	14	38.9	6	16.2
Strongly agree	5	13.9	1	2.7
Medication should be taken if recommended				
Strongly disagree	1	2.8	0	0
Disagree	3	8.3	0	0
Neutral	15	41.7	10	27.0
Agree	16	44.4	24	64.9
Strongly agree	1	2.8	1	2.7
Medication should help with anxiety				
Strongly disagree	2	5.6	0	0
Disagree	4	11.1	3	8.1
Neutral	8	22.2	11	29.7
Agree	16	44.4	17	45.9
Strongly agree	6	16.7	3	8.1
Medication should help with low mood				
Strongly disagree	3	8.3	0	0
Disagree	7	19.4	3	8.1
Neutral	9	25.0	15	40.5
Agree	8	22.2	14	37.8
Strongly agree	9	25.0	3	8.1

	Patients (N = 36)		**Carers (N = 37)**	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**
Medication should help to improve concentration				
Strongly disagree	1	2.8	1	2.7
Disagree	9	25.0	6	16.2
Neutral	7	19.4	17	45.9
Agree	14	38.9	9	24.3
Strongly agree	5	13.9	2	5.4
Medication should help with sleep				
Strongly disagree	1	2.8	1	2.7
Disagree	4	11.1	3	8.1
Neutral	12	33.3	17	45.9
Agree	11	30.6	10	27.0
Strongly agree	8	22.2	3	8.1
Medication should weaken anorexic thoughts				
Strongly disagree	1	2.8	0	0
Disagree	3	8.3	2	5.4
Neutral	12	33.3	9	24.3
Agree	15	41.7	18	48.6
Strongly agree	5	13.9	6	16.2
More research on drug treatment for anorexia nervosa is needed				
Strongly disagree	0	0	1	2.7
Disagree	1	2.8	0	0
Neutral	7	19.4	5	13.5
Agree	14	38.9	13	35.1
Strongly agree	13	36.1	15	40.5
Willingness to take part in research for drug treatment for anorexia nervosa				
Strongly disagree	5	13.9	2	5.4
Disagree	7	19.4	6	16.2
Neutral	10	27.8	18	48.6
Agree	8	22.2	7	18.9
Strongly agree	6	16.7	2	5.4

For the exact wording of the questions, see questionnaire 1 and 2 in the appendix of this chapter.

Table 1.
Frequencies and percentages of answers regarding the overall opinion on drug treatment for AN, important target symptoms, relevance of psychopharmacological research and willingness to take part.

carers, in contrast, was not concerned about weight gain, appetite increase, changes in body shape and metabolism. All the addressed side effects were of concern to patients. For the carers, for most of the questions on side effects, between 20 and 40% of had no particular opinion and thus gave a neutral answer.

	Patients (N = 36)		Carers (N = 37)	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**
Concerns about weight gain during drug treatment				
Strongly disagree	0	0	3	8.1
Disagree	1	2.8	10	27.0
Neutral	2	5.6	11	29.7
Agree	9	25.0	6	16.2
Strongly agree	24	66.7	5	13.5
Concerns about appetite increase during drug treatment				
Strongly disagree	0	0	2	5.4
Disagree	2	5.6	11	29.7
Neutral	1	2.8	13	35.1
Agree	13	36.1	3	8.1
Strongly agree	20	55.6	4	10.8
Concerns about binge eating during drug treatment				
Strongly disagree	1	2.8	1	2.7
Disagree	2	5.6	1	2.7
Neutral	3	8.3	7	18.9
Agree	8	22.2	13	35.1
Strongly agree	22	61.1	10	27.0
Concerns about changes in body shape during drug treatment				
Strongly disagree	1	2.8	2	5.4
Disagree	0	0	5	13.5
Neutral	2	5.6	17	45.9
Agree	14	38.9	4	10.8
Strongly agree	19	52.8	4	10.8
Concerns about changes in metabolism during drug treatment				
Strongly disagree	0	0	1	2.7
Disagree	1	2.8	4	10.8
Neutral	2	5.6	14	37.8
Agree	11	30.6	9	24.3
Strongly agree	22	61.1	5	13.5
Concerns about mood changes during drug treatment				
Strongly disagree	1	2.8	0	0
Disagree	1	2.8	2	5.4
Neutral	4	11.1	6	16.2
Agree	18	50.0	18	48.6
Strongly agree	12	33.3	8	21.6

	Patients (N = 36)		**Carers (N = 37)**	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**
Concerns about tiredness or sleepiness during drug treatment				
Strongly disagree	0	0	1	2.7
Disagree	3	8.3	2	5.4
Neutral	8	22.2	8	21.6
Agree	14	38.9	16	43.2
Strongly agree	11	30.6	7	18.9
Concerns about problems with the heart or the heart rhythm				
Strongly disagree	1	2.8	0	0
Disagree	1	2.8	0	0
Neutral	10	27.8	3	8.1
Agree	14	38.9	8	21.6
Strongly agree	10	27.8	23	62.2
Concerns about nausea during drug treatment				
Strongly disagree	0	0	0	0
Disagree	3	8.3	1	2.7
Neutral	12	33.3	5	13.5
Agree	14	38.9	18	48.6
Strongly agree	7	19.4	10	27.0
Concerns about decreased concentration during drug treatment				
Strongly disagree	0	0	0	0
Disagree	0	0	0	0
Neutral	8	22.2	10	27.0
Agree	16	44.4	15	40.5
Strongly agree	12	33.3	10	27.0
Concerns about changes in laboratory parameters during drug treatment				
Strongly disagree	1	2.8	1	2.7
Disagree	4	11.1	1	2.7
Neutral	12	33.3	6	16.2
Agree	12	33.3	15	40.5
Strongly agree	7	19.4	11	29.7
Concerns about sleep problems during drug treatment				
Strongly disagree	0	0	1	2.7
Disagree	1	2.8	0	0
Neutral	3	8.3	4	10.8
Agree	19	52.8	20	54.1
Strongly agree	12	33.3	10	27.0

For the exact wording of the questions, see questionnaire 1 and 2 in the appendix of this chapter.

Table 2.
Frequencies and percentages of answers regarding the overall opinion on side effects of drug treatment for AN.

4.2 Patients perspective on medication—not suitable to treat anorexia nervosa but of concern because of weight gain as a side effect

The most obvious discrepancy within the patients' answers is that they did not believe medication could help with AN, and were at the same time concerned about appetite increase and weight gain as potential side effects of medication. This finding is of great relevance, as the primary outcome criterion in the majority of clinical studies in AN is an increase in body weight [10, 11, 20]. However, patients may not perceive weight gain as the core problem of AN, because—as stated earlier—self-starvation is their own way to attenuate negative affective states and aversive emotions [12]. Therefore, drug treatment to gain weight alone cannot be perceived as a good treatment option from the patients' perspective.

It is of course necessary for patients with AN to gain weight due to the medical risk associated with extremely low body weight. However, this weight gain should be supported by addressing the underlying difficulties of anxiety and anorexic thoughts.

4.3 Anxiety and anorexic thoughts as outcome parameters for future treatment studies

Our survey showed that anxiety is an important symptom that patients with AN and their carers want to be addressed during psychopharmacological therapy. This is not unexpected, as AN has been found to be closely associated with anxiety disorders [21].

Therefore, questionnaires for anxiety and depression should be used to measure the outcome of RCTs in AN. However, there are many different questionnaires available, which all have their advantages and disadvantages. Thus, the suggestions below may seem arbitrary, however, we would like to provide the reader with some specific suggestions as to how anxiety, depression and anorexic psychopathology can be measured.

The Brief Psychiatric Rating Scale (BPRS) assesses 24 different psychiatric symptoms, among them anxiety, depression, unusual thought content and emotional withdrawal [22]. The Depression Anxiety Stress Scales (DASS) is an instrument designed to measure the three related negative emotional states of depression, anxiety and stress [23]. There is a 21-item as well as a 42-item available. Both these questionnaires could be applied in clinical practice to measure the level of anxiety in a patient with AN or used in future RCTs to test psychopharmacological therapies with regard to their effectiveness in reducing anxiety. In children, the Revised Children's Anxiety and Depression Scale (RCADS), a 47-item questionnaire that measures the frequency of various symptoms of anxiety and low mood, may be used [24]. However, our study sample did not include children and adolescents.

To measure anorexic thoughts, the Yale-Brown-Cornell Eating Disorders Scale (YBC-EDS) [25], the Eating Disorder Examination-Questionnaire (EDE-Q) [26] and the Revised Beliefs about Voices Questionnaire (BAVQ-R) [27], could be used. The YBC-EDS measures core preoccupations and rituals related to eating disorders, the EDE-Q assesses key behavioural features and associated psychopathology of eating disorders and the BAVQ-R is a self-reported measure of patients' beliefs, emotions and behaviour about auditory hallucinations.

4.4 Information on pharmacological treatments for patients and carers

The fact that a large proportion of patients and carers were neutral about certain statements regarding psychopharmacological treatment for AN is not surprising, as

currently no medication is approved for the treatment of AN [10]. Therefore, clinicians could abstain from using psychopharmacological treatment at all and also from informing patients about this opportunity. However, there is positive evidence from clinical studies for a few drugs, and clinicians may share the results of these studies with their patients and carers.

For example, olanzapine was found to be superior to placebo in four published RCTs [28–31] in AN regarding weight gain. It has also been shown to have a beneficial influence on anxiety [32, 33] and sleep [34] in patients with psychosis. Helping with anxiety and sleep were important features of a psychopharmacological drug for patients with AN in our survey. Thus, the high number of people giving a neutral answer in our survey may point to the need for more information to be shared with patients and their carers about the psychopharmacological options.

4.5 Side effects

Most patients had concerns about potential weight gain, increased appetite, and changes in body shape and metabolism. This is understandable, because these are AN-related fears.

However, the last three decades have seen substantial scientific efforts to examine the metabolic side effects of psychopharmacological agents, specifically antipsychotic agents. Weight gain, high blood glucose levels, impaired insulin sensitivity and changes in lipid metabolism have been found to be unfavourable [35]. However, these results were first and foremost obtained in patients with schizophrenia. In patients with AN, however, we have a diametrically opposite metabolic 'starting situation' compared to patients with schizophrenia, as AN patients are significantly underweight, are at risk of severe hypoglycaemia and hypertriglyceridemia, and have been found to have an increased insulin sensitivity [36, 37]. Therefore, the side effects of certain antipsychotics, including olanzapine which increase blood glucose levels, lower insulin sensitivity, elevate triglyceride levels and lead to weight gain [35], do appear to be less problematic in patients with AN.

The evidence from RCTs, however, is insufficient in AN to make firm recommendations; and there are no medications approved for the treatment of AN. Therefore, the above-mentioned conclusions should be drawn with caution, even though they may appear obvious.

4.6 Limitations

Our survey has several limitations. First of all, the applied questionnaires were developed during this QI project and are not established measures for examining patients' and carers' opinions on psychopharmacological treatment. At approximately halfway through the study, we decided to make some minor amendments to the questionnaires, which led to constraints in the statistical evaluation of the survey. Secondly, the sample size of 36 patients and 37 carers is relatively low. However, we hope that by sharing the questionnaires in this book chapter, other scientists will use them for their research which will lead to a broader database. Thirdly, a major shortcoming of this survey is the inclusion of adult patients with AN only, whereas AN is a disorder that starts in childhood and adolescence.

5. Conclusion

We developed two corresponding questionnaires to survey the perspectives of people with AN and their carers on psychopharmacological treatment for AN.

Although most patients did not believe that medication could help with AN, the majority thought that medication for AN should help with anxiety, concentration, sleep problems and anorexic thoughts. Most of the carers shared the view that drug treatment for AN should help with anxiety and anorexic thoughts. Therefore, these symptoms should be given attention when prescribing psychopharmacological agents for people with AN or when planning RCTs for AN.

Most patients had concerns about potential weight gain, increased appetite, changes in body shape and metabolism. However, psychopharmacological drugs may actually help with metabolic peculiarities in patients with AN, including hypoglycaemia.

No psychopharmacological treatment is currently approved for AN, and scientific data on effects and side effects in individuals with AN is scarce. Therefore, although far-reaching conclusions should not be drawn, the available data and information should be shared with patients and their carers to reach the best possible decision on whether drugs should be used for the treatment of AN.

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Conflict of interest

The authors declare that there is no conflict of interest.

Appendix. Questionnaires

A.1 Questionnaire 1: patient views on medication targeting anorexia nervosa symptoms

This questionnaire has been created to help develop research around the use of psychopharmacological medication in anorexia nervosa. Your input will help refine future research projects. Please answer the questions according to what you think. Insert own text if required. Thank you for your participation.

Personal information

1.	My age	Years
2.	My gender	Female/male/other

3. My current treatment: I am currently treated in the following service (FREED, Outpatient, Day-care, SEED, Step-up, Inpatient):

4. Duration of my current treatment in the above-mentioned service:

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Duration of illness

5. For how many years have you had anorexia nervosa?

	Years

Previous drug treatment for anorexia nervosa

	Yes	No
6. I have been treated with a psychiatric medication (medication for your mental health).		
7. I have been treated with antipsychotic medication (such as olanzapine, quetiapine).		
8. I have been treated with antidepressant medication (such as sertraline, fluoxetine).		

9. Are you currently taking/have you previously taken prescribed medication relating to anorexia nervosa? Please specify which.

10. Have you experienced side effects from this medication? Please specify.

11. Do you feel the medication helped?

Opinion about therapeutic effects of a medication for anorexia nervosa

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
12. I think a drug could help treat my anorexia nervosa.					
13. I would consider taking medication for treatment of anorexia nervosa.					
14. I don't want to take any medication.					
15. I would take medication if it is recommended by my therapist or medical doctor.					
16. I would like medication to help me with my anxiety.					
17. I would like medication to help me with my mood.					
18. I would like medication to help improve my concentration.					
19. I would like medication to help increase my appetite.					
20. I would like a medication to help improve my sleep.					
21. I would like a medication to help me with gastrointestinal symptoms such as constipation.					
22. I would like medication to help weaken the anorexic voice or anorexic thoughts.					

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
23. There should be more research on drug treatments in anorexia nervosa.					
24. I would take part in a trial to assist in research into drug treatment for anorexia nervosa.					

25. In your own words, what else would you like medication to help with in overcoming anorexia nervosa?

Views on side effects of a medication for anorexia nervosa

Which of the following potential side effects would you be concerned about in taking a new medication?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
26. Weight gain					
27. Appetite increase					
28. Binge eating					
29. Changes in my body shape					
30. My metabolism could change, making it harder to burn calories					
31. Mood changes					
32. Tiredness or sleepiness					
33. Problems with my heart or heart rhythm.					
34. Nausea					
35. Decreased concentration					
36. Changes in my bloods					
37. Sleep problems					
38. Changes in the way you think					

39. In your own words: What side effect do you fear most?

40. Further comments and suggestions for research around medication targeting anorexia nervosa symptoms.

Thank you for taking part in this survey and answering the questions.

A.2 Questionnaire 2: carer views on medication targeting anorexia nervosa symptoms

This questionnaire has been created to help develop research around the use of psychopharmacological medication in anorexia nervosa. Your input will help refine future research projects. Please answer the questions according to what you think. Insert own text if required. Thank you for your participation.

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Personal information

1.	My own age	Years
2.	My own gender	Female/male/other
3.	Age of my loved one with anorexia nervosa	Years
4.	Gender of my loved one with anorexia nervosa	Female/male/other

5. Current treatment: My loved one is currently receiving eating disorder treatment in the following service (FREED, Outpatient, Day-care, SEED, Step-up, Inpatient):

6. Duration of my loved one's current treatment in the above-mentioned service:

Duration of illness

7. For how many years has your loved one had anorexia nervosa?

	Years

Previous drug treatment for anorexia nervosa

		Yes	**No**
8.	My loved one has been treated with medication for their mental health problem.		
9.	My loved one has been treated with antipsychotic medication (such as olanzapine, quetiapine).		
10.	My loved one has been treated with antidepressant medication (such as sertraline, fluoxetine).		

11. Is your loved one currently taking/has your loved one previously taken prescribed medication relating to anorexia nervosa or other mental health problems? Please specify which.

12. Has your loved one experienced side effects from this medication? Please specify.

13. Do you feel the medication helped them?

Opinion about therapeutic effects of a medication for anorexia nervosa

		Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
14.	I think medication could help my loved one with anorexia nervosa.					
15.	Patients with anorexia nervosa should consider taking medication for treatment of anorexia nervosa.					
16.	I don't want my loved one to take medication.					

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
17. My loved one should take medication if it is recommended by a therapist or medical doctor.					
18. I would want any medication to help my loved one with their anxiety.					
19. I would want any medication to help my loved one with their low mood.					
20. I would want any medication to help my loved one improve their concentration.					
21. I would want any medication to help my loved one increase their appetite.					
22. I would want any medication to help my loved one to sleep better.					
23. I would want any medication to help my loved one with gastrointestinal symptoms such as constipation.					
24. I would want any medication to help weaken the anorexic voice or anorexic thoughts my loved one was experiencing.					
25. There should be more research on drug treatments in anorexia nervosa.					
26. I would encourage my loved one to take part in a clinical trial on drug treatment for anorexia nervosa.					

27. In your own words, what else would you like medication to help your loved one with in overcoming anorexia nervosa?

Views on side effects of a medication for anorexia nervosa

Which of the following potential side effects would you be concerned about, if your loved one takes medication?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
28. Weight gain					
29. Appetite increase					
30. Binge eating					
31. Changes in body shape					
32. The metabolism could change, making it harder to burn calories					
33. Mood changes					
34. Tiredness or sleepiness					
35. Problems with the heart or heart rhythm.					
36. Nausea					
37. Decreased concentration					
38. Changes in bloods					

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
39. Sleep problems					
40. Changes in the way they think					

41. In your own words: What side effect do you fear most for your loved one?

42. Further comments and suggestions for research around medication targeting anorexia nervosa symptoms.

Thank you for taking part in this survey and answering the questions.

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