Anorexia nervosa: treatment expectations – a qualitative study

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Background: Anorexia nervosa is a serious illness with a high mortality rate, a poor outcome, and no empirically supported treatment of choice for adults. Patients with anorexia nervosa strive for thinness in order to obtain self-control and are ambivalent toward change and toward treatment. In order to achieve a greater understanding of patients’ own understanding of their situation, the aim of this study was to examine the expectations of potential anorexic patients seeking treatment at a specialized eating-disorder unit.

Methods: A qualitative study design was used. It comprised 15 women between 18 and 25 years of age waiting to be assessed before treatment. The initial question was, “What do you expect, now that you are on the waiting list for a specialized eating-disorder unit?” A content analysis was used, and the text was coded, categorized according to its content, and further interpreted into a theme.

Results: From the results emerged three main categories of what participants expected: “treatment content,” “treatment professionals,” and “treatment focus.” The overall theme, “receiving adequate therapy in a collaborative therapeutic relationship and recovering,” described how the participants perceived that their expectations could be fulfilled.

Discussion: Patients’ expectations concerning distorted thoughts, eating behaviors, a normal, healthy life, and meeting with a professional with knowledge and experience of eating disorders should be discussed before treatment starts. In the process of the therapeutic relationship, it is essential to continually address patients’ motivations, in order to understand their personal motives behind what drives their expectations and their desire to recover.

Keywords: anorexia nervosa, expectations, treatment, qualitative research

Introduction

Anorexia nervosa (AN) is a serious illness with the highest mortality rate among psychiatric disorders,¹ a poor outcome,² and no empirically supported treatment of choice for adults.³ The process of treatment is complicated, with obstacles such as denial of illness, low motivation to change, striving for thinness, striving for self-control, and ambivalence toward change.⁴ In addition, AN patients’ reduced cognitive abilities and their difficulty with emotional processing, as well as AN’s comorbidity with other psychiatric and personality disorders, are well established.¹⁵⁶

In light of the serious consequences of AN, there is, to our knowledge, little research about these patients’ expectations for treatment. In psychiatric treatment in general, consistency between patients’ expectations and experiences is important for a positive outcome.⁷ Research into the treatment of all eating disorders shows that fulfilled expectations are an important reason for satisfaction with treatment.⁸
Furthermore, in the treatment of eating disorders, Clinton found that a discrepancy between the expectations of patients and therapists concerning possible upcoming interventions increased the risk of early dropout.

Clinton developed a self-report questionnaire, Eating Disorder Expectations, intended for patients with eating disorders and designed to measure both the expectations and the subsequent experiences of therapeutic interventions. When used on adult patients, the results revealed that both practical and personal support from the therapist were extremely important in determining patients’ attitudes to and experiences of treatment. However, in patients with AN, no explicit relationship between pretreatment expectations and subsequent experiences was found, and their satisfaction with the treatment and the therapist could still be high even if their expectations were not fulfilled and recovery was not achieved.

Research on eating-disorder patients’ experiences of treatment is an area that has developed in recent years, although research specifically on AN is sparse. Studies generally include patients with different eating-disorder diagnoses; they observe patients’ experiences of treatment and services. Their results show that patients prefer to receive treatment from specialists on eating disorders, and point out the importance of a holistic approach to treatment that emphasizes the symptoms of the illness and underlying psychological and emotional problems. Furthermore, the personal qualities of the staff, such as being understanding, nonjudgmental, empathetic, and supportive in the therapeutic relationship, are stressed as factors essential to treatment. Experiencing support from a therapist and focusing on eating-control behaviors are predictors of overall treatment satisfaction. Moreover, patients appreciate a warm, caring atmosphere that makes them feel welcome and taken care of – a collaborative therapeutic relationship with a therapist in which quality of treatment, trust in the therapist, and being taken seriously are the most important factors. When patients’ accounts of recovery from AN were explored, the importance of internal motivation for change, feeling safe and supported, tolerating negative feelings, and being less self-critical was highlighted.

Regarding patients’ views of treatment, research specifically on AN is meager. As for patients’ expectations before treatment, there are virtually no studies at all. In light of the serious consequences of the illness and the lack of effective treatment, we need to know more about patients’ understanding of the illness and its treatment. A majority of the research studies on AN patients’ expectations and experiences has a quantitative design, and they most often use self-report questionnaires. However, these techniques are restrictive, since the answers relate to the questions that are asked. Qualitative design, on the other hand, produces a comprehensive view of the subjective thoughts of individuals. To our knowledge, there have been no qualitative studies examining the treatment expectations of individuals who might have anorexia-like eating disorders and who are planning to obtain treatment at an outpatient unit that specializes in eating disorders. One’s personal history and previous experiences most likely influence one’s expectations. For instance, one might have had a catastrophic or an excellent previous experience with treatment, or no previous experience at all: each case affects the patient’s attitudes toward the upcoming or current treatment differently. It is important, before treatment starts, to thoroughly investigate patients’ personal beliefs, imaginings, perspectives, and expectations concerning upcoming treatment, for their potential effects on patients’ attitudes and actions during the treatment itself. The aim of the current qualitative study was to examine potential AN patients’ expectations while they were on the waiting list of a specialized eating-disorder unit.

Methods
In this study, a qualitative content analysis approach was used to explore women’s expectations of treatment. The use of a qualitative design is superior when the intention is to study the subjective expectations of individuals in order to draw inferences from these findings. Content analysis was developed as a method for analyzing a body of text; this qualitative technique involves procedures designed to describe meanings, intentions, consequences, and context, thereby yielding valid inferences from the text.

Procedure
The potential participants were women, between 18 and 25 years of age, seeking help for anorexic problems after being referred by the health services or following self-referral. All the participants were then put on the waiting list. The women were contacted by telephone, by the first author, and were briefly informed about the study and asked to participate in an interview study at the eating-disorder unit. Everyone who was asked agreed to participate, received verbal and detailed written information about the study, and then gave their signed, informed consent.

All the participants were interviewed individually, upon a single occasion, by the first author; each interview lasted...
from 30 to 40 minutes and was audiotaped and transcribed verbatim into textual data by an independent secretary. The question asked was, “What do you expect now that you are on the waiting list for a specialized eating-disorder unit?” The participants were encouraged to speak openly about their thoughts and feelings and were prompted occasionally by the interviewer to elucidate, develop, and expand on their ideas. After a short period of time on the waiting list (a maximum of 30 days), all the patients were offered individual cognitive behavioral therapy. The Regional Ethics Committee in Göteborg, Sweden, approved the study.

Participants
Fifteen women listed consecutively on the waiting list participated in the study at the eating-disorder outpatient unit, Queen Silvia Children’s Hospital, Göteborg, Sweden. At the time of the interviews, the mean age of the 15 participants was 21.7 years (range: 19–24 years). The mean body mass index (BMI), was 17.2 (range: 15–19.6), and the mean duration was 4.8 years (range: 1–10 years). Eight participants contacted the unit themselves (three of whom had previous AN treatment experience), and seven participants (one of whom had previous AN treatment experience) were referred from a health center or psychiatric clinic. Eight participants were studying at a university, and seven were employed (see Table 1).

| Participant ID | Age (years) | Duration of illness (years) | BMI | Diagnosis after first assessment |
|----------------|-------------|-----------------------------|-----|---------------------------------|
| Patient 1      | 23          | 1                           | 16.6| AN                              |
| Patient 2      | 24          | 7                           | 17.7| AN                              |
| Patient 3      | 19          | 6                           | 19.2| AN EDNOS previous AN            |
| Patient 4      | 23          | 7                           | 17.1| AN                              |
| Patient 5      | 22          | 4                           | 17.2| AN                              |
| Patient 6      | 20          | 1                           | 17.5| AN                              |
| Patient 7      | 21          | 4                           | 17.3| AN                              |
| Patient 8      | 23          | 5                           | 19.6| AN EDNOS amenorrhea             |
| Patient 9      | 19          | 2                           | 17.9| AN                              |
| Patient 10     | 20          | 1                           | 16.6| AN                              |
| Patient 11     | 21          | 7                           | 16.2| AN                              |
| Patient 12     | 23          | 10                          | 15  | AN                              |
| Patient 13     | 21          | 6                           | 17.4| AN                              |
| Patient 14     | 23          | 9                           | 18.3| EDNOS                           |
| Patient 15     | 23          | 2                           | 15  | AN                              |
| Mean           |             |                             | 21.7| 4.8                            |

Abbreviations: AN, anorexia nervosa; BMI, body mass index; EDNOS, eating disorder not otherwise specified.

Results
The content analyses revealed 12 categories that described the participants’ treatment expectations. The categories were divided into three main categories: Treatment Content, Treatment Professionals, and Treatment Focus. The categories and main categories reflected the question, “What are your expectations while on the waiting list?” The overall theme found by this study was “receiving adequate therapy in a collaborative therapeutic relationship and recovering”; it illustrated “how these expectations will be fulfilled” (Table 2). All the quotations given below exemplify the categories. Each quotation is followed by the participants’ identification numbers (Table 1) in brackets.

Treatment content
This main category describes expectations of the overall aspects of the treatment offered and encompasses five categories: (1) information, (2) therapy, (3) therapeutic conversation, (4) support and advice, and (5) goals.
Table 2 Subcategories, categories, main categories, and the overall theme from content analysis of narratives about expectations before treatment

| Main category | Treatment content | Category 1: information |
|---------------|-------------------|------------------------|
| Subcategory   |                   | I want information about the methods you offer, and I expect to ask questions about how the treatment works (participants 1, 2, and 7). |
|               |                   | I want to know if I actually have an eating disorder (participant 4). |
|               |                   | I want a medical opinion about my condition and if dancing and yoga once a week are OK (participants 5, 9, and 12). |

Category 2: therapy
- I want cognitive behavior therapy; I have heard that it works (participants 2 and 8).
- I want family therapy because my parents are heavily involved in my problems (participants 7, 8, and 12).
- I have positive experiences of group therapy and expect to get that (participants 8 and 12).
- I want to have the therapy that suits my problems, and I expect it to take some time (participants 3 and 6).
- I want to come for follow-ups (participant 1).

Category 3: therapeutic conversation
- I expect to come here to talk. I expect to talk about my problems and sort them out (participants 1, 2, 4–7, 9, 10, and 13).
- I want to talk about why I am here and what caused my problems (participants 8, 9, 13, and 15).

Category 4: support and advice
- I need support and help in what to do in my daily life and in what I need to change, and advice and instructions on what to do at home (participants 1–3, 5, 7, 9–11, 13, and 14).
- I want support, not sympathy. I need support and help to get well (participants 1, 4, 5, and 6).
- I need some support from my family and friends (participant 12).
- I hope to be helped with all my problems, even if I am not very ill (participants 8 and 9).

Category 5: goals
- I want to get well so I can work and study (participants 4, 5, 8, 11, 13, and 15).
- I want to lead a normal life like my friends, to socialize and have fun, have a lot of energy, and be happy (participants 1, 2, and 11).
- I want to have dinner like everybody else and not think so much about it (participant 11).
- I expect a change in my life, to get some balance and routines (participants 5 and 12).

Subcategories, categories, main categories, and the overall theme from content analysis of narratives about expectations before treatment

**Treatment professionals**

In this main category, the expectations of the unit’s staff were expressed and described in two categories: (1) professional qualities and (2) personal qualities.

**Category 1: professional qualities**
- My view is that there are experts here that know what they are doing (participants 1 and 9).
- I want to see someone experienced in eating disorders with a knowledge of food (participants 3 and 9).
- I want to talk to a psychologist, doctor, or dietician (participants 1, 2, 8, 11, and 13).
### Treatment professionals vs. Treatment focus

| Treatment professionals | Treatment focus |
|--------------------------|-----------------|
| Professional qualities   | Behavioral issues | Physical issues | Psychological issues |
| Professionals with experience and knowledge of eating disorders | Meet someone face-to-face who listens, understands, and respects my situation | Change eating and control behaviors | Deal with body issues | Work with negative feelings |
|                          | See someone not familiar | Know what to eat and how to eat normally | Get strong and alert | Change negative thoughts about food and eating |
|                          |                           | Get control of my eating | Have more energy | Feel all kinds of emotions |

**Category 2: personal qualities**
- I want to be listened to, understood, and taken seriously (participants 3, 6, 11, 13, and 15).
- I want to talk to somebody that gets to know who I am, not only my disorder (participant 11).
- I need someone who can face me and my fears, someone strong-minded that understands my situation (participants 7, 8, and 11).
- I expect to talk to someone that does not take part in my daily life (participants 2 and 7).

The participants expressed confidence in the care unit’s knowing how to treat eating disorders, and they expected to find professionals such as a doctor, psychologist, and dietician specializing and experienced in eating disorders. Furthermore, they expected to meet someone neutral at the eating-disorder unit, with no other connection to their life. They wanted to be treated with respect, listened to, taken seriously, and be given understanding of their situation.

**Treatment focus**

This main category comprised three categories: (1) behavioral issues relating to eating and control, (2) physical issues, and (3) psychological issues, including thoughts and feelings. As a result, expectations of treatment interventions were emphasized here.

**Category 1: behavioral issues**
- I want to know how much a standard portion is and what it is normal for me to eat every day (participants 2, 3, 5, 7, 13, 14, and 15).
- I want to learn how to eat regularly (participants 2, 13, and 14).
- I want to know what kind of food is normal to eat. I want practical advice on food (participants 1, 3, 5, 14, and 15).
- I hope to obtain control of my eating disorder, keep it in check, and not be dominated by the illness (participants 1, 7, and 8).
- I want to let go of my sick control of my eating and of everything else (participants 7 and 10).

**Category 2: physical issues**
- I expect to be able to accept my body, even if I gain weight (participants 3 and 11).
- I want to get away from all my physical troubles and feel strong, with more energy, instead of always freezing and feeling tired (participants 1, 2, 4, 5, and 11).

**Category 3: psychological issues**
- I want to get rid of my distorted thoughts about food and compensating with exercise every time I eat (participants 1–4, 6, 7, 10, and 14).
- I expect to be helped to change my negative thoughts that rule me and my life completely, perhaps find an alternative way of thinking (participants 2, 3, 5, 10, and 14).
- I want to feel more, all kinds of emotions. My feelings are so blunted (participants 1, 3, 5, 6, and 9).
- I want to be able to feel happy, sad, or angry (participant 9).
- I don’t want to be depressed anymore (participants 5 and 6).
- I don’t want to worry about my weight or feel anxiety every time I eat (participants 2 and 6).
- I want to have positive feelings about myself, that I’m capable (participants 5, 9, and 12).

The participants expected substantial, concrete help and information about food and eating – how much and when to eat. Furthermore, they expected to change their eating behavior and learn to eat normally. There were also expectations of change relating to bodily symptoms, such as feeling cold, tired, weak, and infirm, and expectations of change in attitude towards their bodies, to reach self-acceptance and to feel comfortable about their weight gain. The participants expressed strong and disturbing thoughts about food, eating, weight, and compensation, and expected these to change and be replaced by other, more positive thoughts, so that...
the disorder would subsequently disappear. Moreover, there were expectations that depressive and anxious feelings would change and vanish. There was also a need to express all kinds of feelings. The interviewees also expected their self-esteem to change in a positive way, with positive feelings about themselves.

Finally, the four most frequent expectations overall were “change distorted thoughts,” “change eating behaviors,” “lead a normal, healthy life,” and “meet an expert with knowledge and experiences of eating disorders” (see Appendix 1).

The overall theme
The categories and main categories illustrate what the potential patients expected in their contact with the eating-disorder outpatient unit; they reflect the central message on a manifest level. The theme “receiving adequate therapy in a collaborative therapeutic relationship and recovering” was created from the underlying meaning of how the participants understood these expectations.

The crucial question is how these expectations are going to be met. According to the expectations, the treatment should contain a specific therapy method with the opportunity to talk to someone, preferably an expert in eating disorders, who listens and understands the patients’ situations. Furthermore, the treatment should include interventions relating to symptoms of the illness, as well as psychological issues, offered by a therapist who is able to be empathetic and direct in his/her collaboration with the patient.

Discussion
Given that there is a lack of effective AN treatment for adults, we need to know more about the patients’ own understanding of the illness and its treatment. This study explored the expectations of individuals with anorexic symptoms before their assessment and possible treatment at a specialist outpatient eating-disorder unit.

A main finding was that all participants expressed various expectations of reducing AN symptoms, obtaining help, and getting well when meeting the staff at the eating-disorder unit. This expressed motivation illuminates a positive attitude toward attending treatment and an intention to recover. Many clinicians and researchers feel that motivation is insufficient among eating-disorder patients in general and that AN patients in particular have poor motivation at the beginning of treatment. Moreover, AN patients have a reputation for being difficult to treat due to their treatment ambivalence, reluctance to enter treatment, and resistance to change. They view their illness as a chronic condition with negative physical and psychological consequences, and they have low expectations of recovery. In our study, the participants stated positive and hopeful expectations at the time of the interview, with a high degree of expectation in terms of receiving adequate therapy, a reduction in negative physical and psychological symptoms, and recovery. Their statements form a commentary that illustrates the four most frequent categories we found of their expectations: of changing distorted thoughts, changing eating behavior, leading a normal, healthy life, and meeting an expert with knowledge of and experience with eating disorders (see Appendix 1).

However, the patients’ expressed motivation before assessment does not tell us what their motivation to change their eating behavior will be, once they are in treatment. The wish to recover from AN fluctuates in intensity and over time. Decisions to attend treatment, change behavior, and recover must be taken by each individual personally, to achieve a lasting treatment effect. Thus, identifying expectations, motivation, and ambivalence as treatment starts, and continually emphasizing this in the therapeutic relationship, is important in terms of behavioral change and recovery.

The overall positive expectations presented in this study could be partly an effect of the fact that eight participants contacted the unit themselves, three of them with previous treatment experience. Moreover, the participants were young adults with dreams and hopes about possible futures, but with negative experiences of the disease affecting their everyday life and relationships with friends. This could indicate a certain level of motivation for help—that there is still hope of recovering and leading a normal life.

The current results contribute valuable information about expectations being multifaceted and about different aspects of treatment, such as treatment content, treatment professionals, and treatment focus. Individuals who seek treatment expect to be informed about their illness, current condition, and available treatment. This shows an interest in and a need for information and being prepared before treatment. Several findings from previous studies were confirmed regarding treatment professionals and their expert qualities—the ability to create confidence in the therapeutic relationship and to be supportive during the treatment process. In their qualitative study of eating-disorder patients’ experiences of treatment, Pettersen and Rosenvinge report that positive treatment experiences were related to therapeutic relationships that focused on support, empathy, and respect. Clearly, as great expectations are set in terms of staff and relationships, this must be given priority when treatment
starts, by discussing expectations, revealing discrepancies, and negotiating treatment goals in order to enhance the therapeutic relationship. Furthermore, expectations could also be evaluated during the treatment process, in order to evaluate the treatment. This can provide us with important information that can be used in the overall pretreatment evaluation. This could foster the building of the treatment alliance between patient and treatment professional, and could in turn have an important effect on recovery.

There were also expectations linked to eating-disorder symptoms and their effects on eating behavior, the body, thoughts, and feelings. Expectations of concrete measures show that participants have a fairly clear and balanced picture of the problems and obstacles related to the illness, and a wish to change from their current behavior to normal behavior. The Eating Disorder Expectations questionnaire developed by Clinton has three subscales: Support, Insight, and Control. Our results reveal additional aspects of their expectations that could be incorporated and tested for further developing Clinton’s questionnaire (e.g., therapy, goals, professional qualities, and physical issues).

The strength of this study is its qualitative, prospective interview design, which enables the participants to express their thoughts and perspectives. Furthermore, a qualitative content analysis provides an in-depth understanding of the participants’ expectations; one of its strengths is that the interviews are performed with one open-ended question. Starting with “What do you expect?” makes it easier for the participants to express all kinds of expectations.

In qualitative research, credibility, dependability, and transferability are used to achieve trustworthiness. Credibility was established because the first author conducted all the interviews, read through the written text, and carried out the analysis. The second author separately performed an analysis of the codes and categories, whereafter the two authors discussed the results, thereby further contributing to the credibility of the results. In addition, a wide distribution of participants was represented in each category. Dependability was achieved because the interviews were performed over a short period of time, which minimized the risk of inconsistency during data collection. Finally, transferability was facilitated through the description of participants, data collection, and process of analysis. Both authors are qualified, experienced therapists in the field of eating disorders. This adds the perspective of previous experience to the study, which can influence the interpretation of data. Consequently, the authors took this into account when subcategories and categories were analyzed and discussed.

The main limitation of this study was its small sample size and narrow age range. Moreover, all participants were recruited from one specialized eating-disorder outpatient unit, which affected the generalizability of the results.

Young adult women with anorexic problems waiting for treatment at a specialist eating-disorder unit expect to receive adequate therapy in a collaborative therapeutic relationship, and they expect to recover. Specifically, these expectations cover the areas of treatment content, treatment professionals, and treatment focus, and they all express wishes and hopes for support and recovery. In clinical work, patients’ expectations should be discussed as treatment starts, and continually thereafter, to reveal discrepancies and negotiate treatment goals in order to enhance the therapeutic relationship. This places the primary responsibility on therapists’ ability to examine patients’ expectations in detail when treatment is offered. As a basis for this discussion, patients may be given the task of writing a list of their expectations at the start of treatment, based on the main categories presented in this study. As treatment proceeds, the patient’s experiences of both the treatment and the therapist will most likely have an impact on patient’s expectations, which is why this should be addressed by monthly treatment planning. In the process of the therapeutic relationship, it is essential to address patients’ motivations in order to understand the personal motives that drive their expectations and their wish to recover.

Future research could use this study’s main qualitative categories, including how they are stated, to construct a short questionnaire to map AN patients’ expectations before treatment, in line with Nordbø et al. This would be a quantitative validation of current qualitative results, and together the results could form the basis for assessments of expectations in clinical work. In addition, this questionnaire could be used to examine all patients’ expectations in order to find similarities and differences linked to eating-disorder symptoms.

Future qualitative research should also focus on the way patients’ perceptions of their illness affects their treatment expectations. This knowledge could guide us toward creating pretreatment information and standards based on different prerequisites; we could then take them into account, in order to engage with our potential patients in a way that is tailored to suit each individual case. A follow-up study could also investigate current results to see if the participants’ positive attitudes before treatment starts have any impact on motivation, treatment outcomes, or staying engaged with the program. Important questions remain. Do people who are on a waitlist lose some of their positive attitude while waiting
for treatment, and is there a relationship between pretreatment expectations and outcomes?

Conclusion
Young adults with anorexic symptoms who were seeking treatment revealed that their expectations were multifaceted, and the motivations they expressed illuminated their positive attitude toward attending treatment and their recovery. Their expectations emerged as belonging to different aspects of treatment, such as treatment content, treatment professionals, and treatment focus. The overall theme of their expectations was that of recovery after receiving adequate therapy, with interventions targeting physical, psychological, and emotional issues in a collaborative, supportive therapeutic relationship. Patients’ expectations and express motivations should be discussed both before treatment and continually thereafter, in order to enhance the therapeutic relationship.

Disclosure
The authors report no conflicts of interest in this work.

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Appendix 1
In addition, the 12 subcategories presented below show the following ranking from most frequent expectation (1) to least frequent (12):

1. Change distorted thoughts.
2. Change eating behaviors.
3. Lead a normal, healthy life.
4. Meet an expert with knowledge and experience of eating disorders.
5. Meet someone face-to-face who listens, understands, and respects my situation.
6. Get support and good advice.
7. Deal with body issues.
8. Work with negative feelings.
9. A specific psychotherapy approach.
10. Talk about problems.
11. Be informed about treatment.
12. Change control behaviors.