PATIENT EXPERIENCES

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# Effective nursing care of adolescents diagnosed with anorexia nervosa: the patients' perspective

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**Aims and objectives.** The purpose of this study is to develop – from the patients' perspective - a tentative theoretical model explaining the effectiveness of inpatient nursing care of adolescents diagnosed with anorexia nervosa.
**Background.** The continuous and direct involvement of nurses with patients is likely to play a significant role in the recovery process of patients with anorexia nervosa. However, only limited evidence is available on what patients with anorexia nervosa themselves consider important and effective in terms of nursing care.
**Design.** The design of this study was qualitative.
**Methods.** A grounded theory approach was applied where 13 adolescents with anorexia nervosa were interviewed to generate data for the model.
**Results.** Participants stated that nurses contributed significantly to their recovery from anorexia nervosa. Three recurring themes emerged from the data: (1) normalisation, (2) structure and (3) responsibility. The focus of nursing care with respect to these themes shifted during the phases of recovery.
**Conclusions.** Based on patients' experiences a theoretical model is developed describing effective nursing care of adolescents diagnosed with anorexia nervosa. Patients identified the key components of this model as essential to their weight recovery.
**Relevance to clinical practice.** The model may be used to improve the quality of nursing care of adolescents diagnosed with anorexia nervosa through analysis of current practice with respect to the key components of our model. Interventions that are based on these components closely follow the patients' needs.

**Key words:** adolescents, anorexia nervosa, eating disorder, nurses, nursing, weight restoration

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## Introduction

Anorexia nervosa is an eating disorder predominantly affecting girls and young women. In industrial countries, the disorder's prevalence is 370 per 100,000 (Hoek & van Hoeken 2003). Anorexia nervosa may affect a patient's mental and physical condition to such an extent that hospital admission is inevitable. Approximately 15% of patients suffering from anorexia nervosa die from the disorder (Dutch Committee for the Development of Multidisciplinary Guidelines in Mental Health Care 2006).

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The Dutch Multidisciplinary Guideline for Eating Disorders (2006) recommends that patients with severe symptoms of anorexia nervosa be treated in specialist clinics. The central aim of inpatient treatment programmes is to regain normal body weight. Regaining normal weight is considered a prerequisite for full personal and social recovery. Patients with anorexia nervosa stressed the importance of a good therapeutic relationship. In their opinion, caregivers should be empathic, understanding, supportive and non-judgemental (George 1997, Button & Warren 2001, Tozzi *et al.* 2003, Colton & Pistrang 2004, de la Rie *et al.* 2006, Federici & Kaplan 2008, Tierney 2008). Nursing staff caring for patients with anorexia nervosa recognise the importance of empathy and support, but also report that mutual feelings of mistrust and the need to enforce regulations may thwart the development of a therapeutic relationship (King & de Turner 2000, Ramjan 2004, Ryan *et al.* 2006).

Apart from the physical aspects of recovery, attention should be given to the individual psychosocial and emotional needs of patients (Button & Warren 2001, Colton & Pistrang 2004, Tierney 2008). Furthermore, adolescents with anorexia nervosa have indicated a need for experienced professionals who recognise and can explain behaviour that is symptomatic of their illness (Colton & Pistrang 2004, Tierney 2008).

It is conceivable that, in cooperation with other professional disciplines, the continuous and direct involvement of nurses plays a significant role in the patients' recovery process. Therefore, the views of adolescents diagnosed with anorexia nervosa on aspects of nursing care that contributed to their recovery were further explored and elucidated in the present study.

The main question in the study is:

Which aspects of nursing care do adolescents diagnosed with anorexia nervosa believe contribute to regaining their body weight?

Weight recovery during hospital admission is achieved largely by restoring a normal eating and exercise pattern. Consequently, the main research question is divided into two sub-questions:

1 Which aspects of nursing care do adolescents diagnosed with anorexia nervosa believe contribute to restoring a normal eating pattern?
2 Which aspects of nursing care do adolescents diagnosed with anorexia nervosa believe contribute to restoring a normal exercise pattern?

The purpose of this study is to develop a tentative theoretical model explaining effective nursing care with respect to weight recovery, based on the patients' experiences. This model may be used to develop nursing interventions that closely follow the 'needs' of patients and are in agreement with demand-driven care.

## Methods

### Research design

A qualitative research design is most appropriate for describing and analysing patients experiences and perspectives. In that context, the grounded theory approach according to Strauss and Corbin (1998) was chosen: the experiences of the patients served as a basis for constructing a theoretical framework for the effectiveness of nursing care in adolescents diagnosed with anorexia nervosa. This study was funded – and approved by – the scientific and ethical review board.

### Population

The study was conducted in an inpatient unit of a centre specialised in treating eating disorders. This unit treats young people of 18 and under who suffer from eating disorders. After initial psychiatric assessment, patients enter a program with the objective to restore body weight and eating patterns and to normalise anorectic cognitions, body image and family and social functioning. Weight gain is targeted at 0·5–1·0 kg/week. Weight recovery is defined as a weight within the normal range for age ( > SD-1·5 corresponding with a body mass index of approximately 19 $kg/m^2$ for adults). For female patients a regular menstrual cycle, defined as three menstrual periods with 3–5 week intervals, is an additional requirement (van Elburg *et al.* 2007).

In 2006, 26 adolescents were treated, 15 of them suffering from anorexia nervosa. Of the group of 15 patients with anorexia nervosa, 14 were discharged having a Body Mass Index (BMI) within the normal range again. This indicates that treatment in this centre is successful as far as weight recovery is concerned.

The following inclusion criteria were applied:

- age between 12–18;
- diagnosed with anorexia nervosa according to DSM-IV-TR criteria;
- discharged after having received clinical treatment;
- weight recovery to a value within the normal range for age;
- discharged from the centre in the last three months before data collection;
- sufficient command of the Dutch language to be interviewed.

The participants were selected on the basis of a convenience sample among all patients who were dismissed during

  

the research period. Patients who met the inclusion criteria and their parents were informed about the research project, both orally and by information letter. Having obtained consent from both the patient and parents, the patient was included in the study.

The sample comprised 14 female adolescents diagnosed with anorexia nervosa. One patient refused because she was not interested in participation. The average age was 15 (range 13–17 years). The average time of hospital admission was 131 days (range 67–246 days). The average BMI of the participants upon admission was 3·22 standard deviations below the standard mean for age. Of the 13 participants, 12 had first been in a general hospital because of their critical physical condition.

### Data collection and analysis

Data collection took place between June 2006–March 2007. Data were collected through individual semi-structured in-depth interviews. Each interview started with the interviewer showing a chart of the participant's weight progress over the period of admission. Following discussion of the chart, participants were asked to respond freely to a general question about the aspects of nursing care that contributed or, conversely, impeded their weight recovery. The relevant aspects of nursing care were further explored during the interview.

Data were collected and analysed in a cyclical pattern: intermediate analyses of interviews directed the course of subsequent interviews (Strauss & Corbin 1998). In total 13 interviews of approximately one hour were conducted and recorded on audiotape. The first three interviews were analysed in detail among the research group (two researchers, one associate professor in mental health nursing) to evaluate the interviewing techniques applied.

Each interview was transcribed *verbatim* and analysed using the software programme 'winMAX pro 98'. Two researchers (JO/EM) analysed the transcript of the first interview separately to create a list of code words reflecting specific factors that had an impact on the participant's weight recovery process. With each analysis of subsequent interviews, new code words were added to the original code tree (open coding). The two researchers coded 10 interviews independently. Differences of opinion, were discussed so as to arrive at a consensual interpretation of the research data. Two interviews were coded by one researcher only. Due to technical problems during recording, the last interview could not be transcribed and was excluded from further analysis. Through a process of axial coding (Strauss & Corbin 1998) central concepts pertaining to nursing care provided to anorexia nervosa patients were deducted from the entire data set. These concepts are the basis of the model presented here.

The research group met periodically to discuss substantive and methodological aspects of the study on the basis of memos resulting from data analysis. The results and conclusions were submitted for review to two expert nurses of the eating disorders specialist centre.

## Results

The aspects of nursing care which in the patients' opinion contributed to regaining body weight can be described on the basis of the following three core categories: (1) normalisation, (2) structure and (3) responsibility. We explored these categories on the basis of a time line from the moment of admission to the time of discharge from the centre. This period was divided into 3 phases.

### Phase 1

Phase 1 begins with the patient's admission to the inpatient unit of the centre. The interviews showed that the first week was crucial to the treatment process. Learning to eat again was the central theme in this phase. The nursing staff supported the patients in normalising their eating pattern and exercise pattern from the first day of admission. The nurses were very insistent: respondents felt perplexed when they had to join their first group meal immediately after the intake interview. One of the respondents stated:

> That was really rotten. It was like: draw up your chair and eat a chocolate sprinkles sandwich. I hated that and you really had to add loads of toppings. I first thought the nurse was joking, but she wasn't. (patient 12, age 16)

Patients experienced extreme stress during these first meals. They were expected to follow the directions of the nurses and eat along with the other patients. The food evoked much aversion. The patients did not actually want to eat and were terrified of gaining weight.

In retrospect, the patients regarded the directional actions of the nursing staff as very helpful. They told the interviewers that they had lost all sense of how to eat properly and that they had needed the structure-based interventions to be able to resume their normal eating pattern. They had to relearn how to eat and gradually became aware that normal eating was, in fact, legitimate:

> They [the nurses] kept on telling me that I had to eat faster. I just did not understand it. I thought, I can't eat any faster and no one had

ever told me that I eat too slowly. At first, I thought that I brought the fork to my mouth too slowly, until a nurse told me I had to chew more quickly. Then I got it. With hindsight I realised that I ate very little for a very long time, so I wasn't really used to it any more. I started to pay attention from then on and saw that I had to chew more quickly. (patient 3, age 15)

The patients indicated how important it had been during this initial phase that all responsibility for eating and exercising was taken away from them, as they were unable to break their compulsive patterns by themselves. Firm nursing interventions proved to be of great importance: they chose the sandwich toppings for the patients, they served the hot food and they prohibited the patients from exercising after the meals:

It was a good thing that someone took over so that I did not have to think for myself. Just so that I did not have to make any decision at all. (patient 5, age 15)

The first period after admission, a nurse was constantly around. New patients were to stay in the living room and could only leave with permission. The respondents indicated that the physical presence of nurses at this stage was vital to the process of restoring normal behavioural patterns: the presence of nurses made it impossible for them to exercise excessively. Patients felt strongly dependent on the presence of nurses. In this sense, they were ambivalent: on the one hand, they felt anxiety because they were forced to battle their compulsive behaviour; on the other hand, they were offered support based on continuity and structured care.

The patients also indicated the importance of the constant flow of information about anorexia nervosa from the nurses in addition to the interventions referred to above. The staff's explanation of the direct physical consequences of being underweight was considered to be of particular value. This knowledge raised the patients' awareness of anorexia nervosa having extreme adverse effects on both their health and their future. The patients frequently saw only the 'positive' effects of having a slim body.

The respondents also regarded the presence of a group of peers with a similar disorder as being a factor contributing to the process of relearning how to eat. New patients were able to observe peers eating food without feeling the anxiety they felt themselves. They also observed that fellow patients enjoyed more privileges as treatment progressed, such as going back to school or taking up sports. Therapeutically, the nursing staff facilitated interactions between patients in various phases of treatment during daily events, such as morning assemblies and group meals. In this way, new patients were able to overcome difficult times by leaning on experienced patients who were in a more advanced stage of recovery. Nurses thus promoted support and identification within the peer group:

There were some girls who had already made progress and they were my role models. I really wanted to be like them. I thought: that's actually how I would like to be. They finished their meals quickly, as I used to do before and with ease. That helped. The nurses often asked members of the group – during morning assembly, for instance – how they had reached their goals, how they had taken their first steps towards eating and how they had coped when times were difficult, like when you're sad and think that you'll never make it. This made the group feel involved with each other. The group gave specific examples from everyday life. They gave reassurance by saying that things would work out. (patient 6, age 13)

Specific nursing attitudinal aspects surfaced repeatedly during the interviews. Attitudes such as involvement, reliability, availability, clarity and insistence, were qualified as essential to successfully normalising eating pattern and exercise pattern. These attitudinal aspects contributed to creating a good alliance where nurses could offer empathic support and, at the same time, exercise the requisite pressure to change behaviour. The patients indicated that the nursing staff's emotional availability was particularly vital: are you prepared to make time for me and do you notice when I have a hard time?

### Phase 2

Phase 2 focuses on two aspects: (1) having the patients take back responsibility for eating and exercising; and (2) normalising everyday life in terms of school, recreation, peer relationships and other age-specific activities.

Patients felt support through the use of an individual action plan. The plan, which included repeated moments of evaluation, contained specific details of which responsibilities were given back to the patients and at which stage. For instance, in the first week, patients were asked to prepare their own between-meal snacks under the guidance of a nurse. If they managed this assignment well, they were made responsible for choosing their own sandwich toppings during lunch. The respondents indicated that preparing the plan in collaboration with the nurses had a very encouraging effect. It allowed them to show what they had learned. They had regained the power to direct their own eating and exercise pattern under the supervision of a nurse and felt the hope that they might actually be able to regain the trust and confidence of their family and friends:

  

It just felt nice that I could show that I could do everything by myself again … and that I did not have to be told everything I had to do. (patient 7, age 16)

In other words, the action plan helped the patients step by step to regain control over their eating and exercise habits and, hence, to take back their own lives. The nurses offered them the space to take control during the difficult periods of food intake by letting them make their own choices and evaluating those choices afterwards. In those evaluations, patients were given the opportunity to explain their choices, which helped them discover specific irrational cognitions and habits, such as a fear of specific products.

The process of the patients collaborating more closely with the nurses was considered material to this phase. Whilst nurses initially performed a mainly controlling and directional role, they now shifted their focus towards creating trust. Patients indicated that they were building a closer connection to one or two nurses, generally to the nurses they saw most frequently and who showed their involvement with the patient by keeping an open mind and taking initiatives to connect. A relationship of trust also grew because nurses showed expertise in the field of eating disorders. Trust made it possible to talk about subjects the patients considered extremely embarrassing, such as their own perception of their bodies.

The second phase was further characterised by the patients still feeling ambivalent about their eating disorder and the need to overcome that disorder. They wished to return to a normal life, but still felt deeply anxious about consuming food and gaining weight. To reduce that anxiety, patients indicated how important it was for them to still receive in-depth information about eating disorders. Modelling also proved to be very important in this phase. The nurses acted as role models by joining the meals and showing a normal eating behaviour, but also by participating in recreational activities. For instance, they showed patients what was considered a normal pace of cycling and that it was perfectly normal to stop cycling to take shelter from the rain. The patients learned that bicycling was a relaxing activity and that it was more than just burning calories. If accompanied by informative explanations, this modelling behaviour was often felt comforting:

I had no idea anymore of what normal exercise was, I had completely lost that. I even figured out how often I had to walk to the bathroom. If we went out for a walk, I always walked up front, setting the pace, which was quite fast. But then the nurses told me to walk more slowly and showed us what was normal. (patient 5, age 15)

In this second phase, the patients returned home for the weekends. Several patients stated that they frequently lost weight over the weekend because they missed the structural regime of eating and exercising. In response to such signals, the nurses offered the parents an opportunity to join a meal at the centre. They could then instruct the parents how to encourage their daughter to continue eating whenever the fear of gaining weight came to the fore. The parents also learned how to turn meals into a more positive and less stressful experience. The patients indicated how important it was to them that the rules at home were the same as those that applied at the centre. This reduced the risk of weight loss over the weekends at home and also reduced the number of conflicts over meals between the parents and the patient.

All interviews showed the importance of the patients being able to return to normal life one step at a time. Starting with easy exercises and activities, the patients learned to feel positive about themselves and were able to increase their self-esteem. They undertook some of the activities together with the nurses, so that they could benefit from hands-on support and counselling by the nursing staff. Having the patients take one step at a time, by giving them clear and specific assignments, provided the necessary structure. The patients also indicated the importance of evaluating all exercises to make problems visible and receive positive reinforcement:

I started to have a small taste of normal life again. We took a bicycle ride, had a swim and watched horses. It was really, really helpful. It shows why you're doing it and you discover that not all things are as scary as they seem to be at first. (patient 9, age 14)

In this phase too, patients indicated that feedback from their peer group helped them continue treatment. The nurses continued to encourage patients to share experiences so that more experienced patients could act as role models for those who had not yet advanced so much.

### Phase 3

Phase 3 is the final phase of the clinical treatment. The patients indicated that this was a very important phase in preparing them for discharge from the centre. Phases 1 and 2 had offered the patients structure and tools to experiment with their new life in a relatively secure environment. Nonetheless, the patients felt that it was still a long road towards overcoming their fear about eating. This is why the continuing support and counselling by nurses remained essential.

In phase 3 of the treatment process, the patients themselves were largely responsible for their eating and exercise habits.

The nurses gave support by offering exercises to vary eating behaviour in everyday life, for instance during lunches at school. The patients stayed at home during the weekend and went to their own schools on Monday. Their stay outside the clinic was later on extended with another day, so that in the end, patients returned from their leave Tuesday evening. The patients discussed difficult situations they encountered on return to 'normal life'. In their 'new bodies' they had to reconnect with peers outside a clinical setting. This evoked great uncertainty and anxiety about their own identity and body image. Fear of rejection was predominant among the patients. They considered the support by nurses to be very valuable in this regard. The nurses continued to confront the patients with their deviating eating behaviour and exercise behaviour. They also helped patients fine-tune their irrational cognitions:

> I was afraid of how I was starting to look. The nurses helped me put things into perspective […] which slowly made me realise that something was wrong in my head. There was still that other image in my head, but I gradually realised that it was a wrong image. I agreed with the nurse more and more often. (patient 2, age 16)

In this final phase towards weight recovery, the nurses created space for the patients to practise managing difficult situations they faced in everyday life. They created this space by taking some distance from the patients. Their structure-providing presence during earlier phases was gradually reduced. Instead, the patients were given responsibility for their eating and exercise habits. The nurses encouraged the patients to find their own solutions to problems they encountered. According to the patients, the fact that the nurses did stay focused on them was an essential condition of their being able to practise the newly learned skills effectively. It was also evident from the patients' experience that too much leeway offered by nurses could cause a relapse:

> I then was in the final phase and started to exercise like crazy, taking walks before and after meals and whenever I had some time off. Well, I was in the final phase after all and had been given back full responsibility. (patient 2, age 16)

A balanced measure of distance and closeness was necessary for the patients to regain control over their newly-learned eating pattern and exercise pattern. In the limits of the space offered to them, the patients attached great value to still being able to turn to the nursing staff if they had questions or wished to reflect on new experiences. The respondents highlighted the importance of being trusted by the nurses, since that made them aware of their own potential and increased their self-esteem.

Also of importance to the patients was that the nurses were able to discover the person behind the eating disorder. The young women wanted their abilities to be seen again and wanted to be reassured that their pre-anorexia dreams and ideals could actually be pursued once more. They felt especially supported by an attitude of respect and equality by the nurses. The patients noticed that their eating disorder was no longer the only topic of conversation and that they were preoccupied with other things, such as being in love, using makeup and having fun. The nurses made an active contribution to this development by constantly stimulating the patients with humour and new challenges.

Because the patients increasingly spent time at home and started to attend their own school again, their confidence in being willing to take responsibility for their own actions in terms of food consumption and daily activities also grew. The increase in self-esteem added to the desire to be discharged from the centre:

> Then you return home and see your friends again, you start to do things you used to do and also start to do fun things. After a while you were allowed to go out and notice that it is much more fun than having an eating disorder. (patient 5, age 15)

## Discussion

This study focused on the aspects of nursing care that adolescents diagnosed with anorexia nervosa believe do contribute to regaining their body weight. Recovery in patients with anorexia nervosa is often a long-lasting process, with gradual changes in eating and exercise pattern, body weight, cognitions, self-esteem and personal and social functioning. Our study focused on body weight as a strong and objective indicator for recovery during clinical treatment. However, we do emphasise that a comprehensive treatment program for adolescents with anorexia nervosa should also give sufficient (and balanced) attention to the emotional and psychosocial functioning of patients with anorexia nervosa, as these are key long-term predictors for recovery.

Although the patients' perspective has been investigated before (George 1997, Button & Warren 2001, Tozzi *et al.* 2003, Colton & Pistrang 2004, de la Rie *et al.* 2006, Federici & Kaplan 2008, Tierney 2008), to our knowledge this is the first study that specifically investigates the extent to which nursing care contributes to body weight recovery of adolescents diagnosed with anorexia nervosa. Through qualitative analysis three core categories emerged from the data: responsibility, normalisation and structure. The way each of these take shape in nursing care depended on the patient's recovery phase. Three distinct phases were identified, during

  

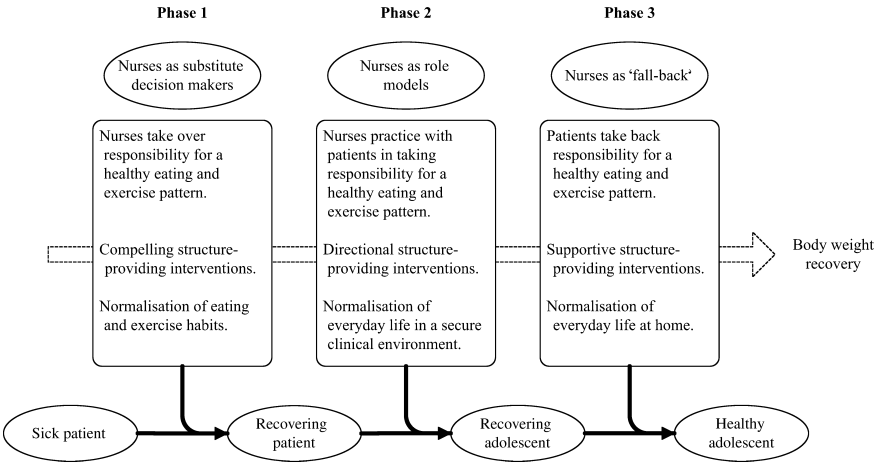


**Figure 1** Central aspects in nursing care of adolescents diagnosed with anorexia nervosa.

which nurses subsequently acted as: substitute decision makers, role models and as a fall-back to the patient. Figure 1 shows a model of nursing care where these nursing roles and characteristics of responsibility, normalisation and structure are presented during each phase of recovery.

Responsibility for eating and exercising was almost entirely taken over by nurses immediately after admittance to the centre during phase 1. This proved to be crucial to the process of recovering from a disturbed eating and exercise pattern. In the course of the treatment, responsibility was gradually given back to the patients, depending on their capacities (skills, motivation, insight) and body weight increase. This concurs with Colton and Pistrang (2004, p. 314) who describe this responsibility issue as 'the necessity of taking control while also encouraging young people with anorexia to take responsibility for their own recovery'.

The focus of normalisation was on relearning a normal eating and exercise pattern during the initial phase. This continued, but the focus shifted gradually towards normalisation of everyday life activities touching on restoring social relationships and community participation (see also: Tozzi *et al.* 2003, D'Abundo & Chally 2004); initially in the secure boundaries of the centre (phase 2) and later in the real world (phase 3). The importance of teaching a normal eating pattern was also described by Zandian *et al.* (2007).

Structure-providing nursing interventions matched the progress made by the patients. At first they were compelling and intrusive. These interventions were often experienced as stressful and frightening at the time, but in retrospect they were mostly rated as positive. Without them, patients would not have succeeded in abandoning their pathological dieting and exercise habits. The character of structure-providing interventions changed into guidance and support over the phases where patients focused on returning to a normal life. This underscores the importance of balancing restrictions to prevent patients from feeling punished rather than helped (Colton & Pistrang 2004).

### Limitations

We applied measures to assure credibility of our findings (triangulation, peer debriefing). A limitation of the study is that we interviewed recovered patients in a sample of female patients only. This resulted in limited variation of the sample, which did not allow for theoretical sampling. The retrospective design of our study may have introduced some recall bias.

### Relevance to clinical practice

The results of this study may be used to improve the quality of nursing care of adolescents diagnosed with anorexia nervosa, by analysing how the components of our model are represented in existing treatment plans. It may explain why specific treatments do not (fully) have the intended result, so that structured improvement plans can be developed to increase the quality of care of this highly complex group of patients.

## Conclusion

A grounded theory approach was used to study the aspects of nursing care that contribute to body weight recovery according to adolescents with anorexia nervosa. A tentative model is presented identifying the key characteristics of nursing care with respect to anorexia nervosa. This model is based on the core categories that emerged from the data: (1) responsibility, (2) normalisation and (3) structure. It is suggested that additional research is done to support the model we presented. Credibility of our findings could be

improved by contrasting them with the perception of adolescents who did not recover.

The gradual transfer towards a focus on normal life activities and taking back responsibility proved to be a subtle process. It required nurses to constantly assess the balance of the patient's weaknesses and strengths, as any disturbance may increase the risk of relapse. This indicates that nursing care of adolescents suffering from anorexia nervosa is specialist work. It is essential that nurses have knowledge and skills at a specialist level to provide proper care to this patient group. It is, therefore, recommended that nurses receive advanced training to be able to work effectively with this population.

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## Contributions

Study design: JO, BM; data collection and analysis: JO, EM, BM and manuscript preparation: JO, EM, BM, MK, AE.

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