

Aftercare in patients with anorexia nervosa

A descriptive study

Final draft

August 17, 2012

Intended Journal: Journal of Clinical Nursing

Reference style: According to the journal

Number of words: 3,000 - 5,000

English summary: 269

Dutch summary: 291

Research report: 3384

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INTRODUCTION

Anorexia nervosa is a psychiatric disorder whereby patients do not maintain their body weight at or above a minimally normal weight for age and height. The way in which a patient's body weight or shape is experienced is disturbed. Despite severe underweight, the patient experiences an intense fear of gaining weight. (American Psychiatric Association 2001).

Anorexia nervosa is a serious disease which affects patients' physical, psychological, and social development and functioning (Strober *et al.* 1997).

The incidence of anorexia nervosa in the Netherlands is estimated at 8 cases per 100,000 per year (Hoek & van Hoeken 2003). However, incidences are varied widely among different age groups, and are grossly underestimated because not all subjects are referred to health care facilities (Hoek & van Hoeken 2003, Hoek 2006).

To improve the condition of the patient with anorexia nervosa, treatment is focused on physical recovery, motivation, psycho-education, rehabilitation and relapse prevention (National Steering Committee Guideline Development in Mental Health 2006).

Nevertheless, worldwide a mortality rate of five percent of adult patients with anorexia nervosa, in which this study focuses on, is given. Among surviving patients, less than 50% recover, whereas 33% improve, and 20% remain chronically ill. (Steinhausen 2002).

Despite successful treatment in hospital, worldwide 30 to 50% of patients with anorexia nervosa relapse within one year after discharge (Keel & Brown 2010, Pike 1998). The risk of relapse is the highest in the first 18 months after discharge (Carter *et al.* 2004).

Relapse can be defined as the (re)occurrence of a number of core symptoms of anorexia nervosa (see Table 1), after earlier some treatment response has occurred (Pike 1998).

To prevent relapse, the Dutch Multidisciplinary Guidelines for Eating Disorders (2006) recommend teaching patients to recognize early signs of relapse and to initiate preventive actions when these signs occur. Nurses have an important key role in relapse prevention. However, the exact way in which nurses should work out relapse prevention methodically, especially after discharge, is not described.

The Dutch Anorexia Relapse Prevention Guideline has been developed to work structurally on relapse prevention of patients with anorexia nervosa after discharge. It consists of a Periodic Anorexia Check (PAC)-program, comprising drawing up a relapse prevention plan (RPP) and working with this plan, both at home and in the clinic through comeback sessions, called PAC-meetings (Berends *et al.* 2010).

An individual RPP is drawn up in the final stage of treatment. Triggers, early signs, and actions are described in four stages, from the first signs of deterioration to full relapse. After discharge, the patient and nurse discuss the condition of the patient through PAC-meetings, during the high-risk period in a low frequency, depending on the condition of the patient. Both can decide to extend the period in case of prolonged vulnerability to relapse. (Berends *et al.* 2010).

Problem statement

The PAC-program is implemented in a specialized eating disorder clinic. Recently, first patients completed the program. However, it is unknown how these patients experienced this program.

Aim

The aim of this research is to gain a profound insight into the experiences of patients who participated in the PAC-program. The study leads to knowledge about patients' appreciation of the program, as well as insight into factors that contribute to or hinder successful application of the PAC-program. On the basis of this knowledge the program can be adapted in such a way that it is better tailored to the patients' preferences. In addition, the effectiveness of the program expected is to be enhanced.

Research questions

What are the experiences of adult patients who participated in a relapse prevention PAC-program of a specialized eating disorder clinic, after discharge from clinical treatment for anorexia nervosa? What factors contributed to and hindered patients the effectiveness of the PAC-program?

METHODS

Design

A descriptive qualitative research design is chosen, to provide an in-depth understanding of the experiences of patients with anorexia nervosa concerning the PAC-program (Polit & Beck 2008).

The study was approved by the scientific research committee of the organization in which the study took place.

Setting and participants

Participants were selected from a top clinical centre for the diagnoses and treatment of children, adolescents and adults with eating disorders (anorexia nervosa, bulimia nervosa, and binge eating disorder). It is a part of a large nonprofit mental healthcare institution in the Netherlands.

Participants were required to meet the following inclusion criteria: aged 18 years and older; treated for anorexia nervosa (DSM IV-TR 2001); in possession of a relapse prevention plan at the start of the PAC-program; participated at least 18 months in the PAC-program and; able to understand and speak Dutch.

Participants were selected based on convenience sampling among all patients who participated during winter 2011, and spring 2012, in the PAC-program.

Patients who met the inclusion criteria were invited face-to-face by their clinician or by the researcher via telephone to participate in this study. Patients were informed by the researcher about the study, both by information letter and via telephone. Patients were included after obtaining informed consent. The baseline characteristics are respectively shown in Table 2.

The sample comprised 14 female adult participants. Of this sample two patients refused to participate without giving a reason. Two others refused because they did not want to discuss their illness history again. The average age was 22 (range 18-32 years). The average time of participating in the PAC-program was 21 months (range 18-31 months). Of the ten participants, one participant was readmitted during the PAC-program due to full relapse.

Data collection and analysis

Data collection took place in spring 2012 via semi-structured interviews.

In preparation of the interview, the illness course of the past 18 months was extracted from patients' file data. A summary was written of what has been discussed between the nurse and the patient in every PAC-meeting.

An interview protocol was constructed based on the organization of the PAC-program and the structure of the Anorexia Relapse Prevention Guideline. Questions were focused on the period of aftercare in its entirety, on the first period after discharge, and on the period following. Next, the different components of the relapse prevention plan were discussed: the preparation stage; the identification of triggers and early signs of relapse; the formulation of actions to prevent further relapse; and the help of social network. Also the help of nurses and the usefulness of the PAC-meetings were evaluated.

The interview, of approximately one and a half hour, took place at a location on the patient's choice. One patient chose to be interviewed via e-mail because a face-to-face

interview was considered as too burdensome. Two patients chose to be interviewed at home; from one of them their partner was present. All other patients were interviewed at the clinic.

Data were collected and analysed separately. Audio taped interviews, used as data sources, were transcribed verbatim.

To organize qualitative data, computer theory-building software NVivo9 was used. The most widely used procedure to organize data, is to develop a category scheme (Polit & Beck 2008). A category scheme can be derived from the data, or from previous related studies or theories. The aim of this study was to describe a particular experience related to a methodical approach aimed at the prevention of relapse in patients with anorexia nervosa. To this end, before data collection, a fairly concrete category scheme was generated based on the structure of the Anorexia Relapse Prevention Guideline.

Qualitative directed content analysis was used as analytical approach to describe the data and search for relationships within the data (Polit & Beck 2008). The structure of codes and categories was further elaborated and refined as the research process progressed. The coding process involved the arrangement of words, sentences or paragraphs that relate to the same meaning into meaning units and labeling meaning units with a code according to the content they represent. Finally coded material was grouped together based on shared categories and concepts (Polit & Beck 2008).

Research quality

To enhance transcription rigor, the transcriber was trained not to alter (deliberate, accidental or unavoidable) the data, in addition, a guideline for handling potential problems was developed. (Polit & Beck 2008). Before the start of the analytical process, the researcher checked randomly the accuracy of transcribed data.

The interviewer objectively and critically listened to the tape recorded interviews to improve subsequent interviews (Polit & Beck 2008). Three interviews were discussed within the research team to evaluate the interview structure and techniques.

To ensure coding consistency across interviews, a single member of the research team (ML) coded the entire data set. Because it was expected that initial coding would not bias the identification of relevant text, coding began immediately with predetermined codes (Hsieh & Shannon 2005). To evaluate and enhance reliability a log of decision points were kept by the primary researcher (ML), and discussed within the research team (ML, BM, and TB) to check the accuracy of coded data and the implications for a description of the data (Baarda *et al.* 2005, Creswell 2007, Polit & Beck 2008).

Research ethics

The handling of personal data complied with the Dutch Personal Data Protection Act (Data Protection Board, 2000). A subject identification code list was used to link the data to the individual subjects. The code list, as well as tape recordings, were stored on a password-protected computer. The investigator safeguarded the key to the code, the research team (ML, BM, TB) were the only persons who had access to the source data.

RESULTS

The experiences of the interviewed patients, including the identified contributing, and hindering factors concerning the PAC-program will be described in the following section.

General evaluation of the PAC-program

The PAC-program consisted of drawing up a relapse prevention plan (RPP) and working with this plan, both at home and in the clinic through PAC-meetings.

Patients were generally satisfied with the program. On average they rated the program with a seven, with a possible scoring range between zero (bad) and ten (good). Of the PAC-program, patients valued the possibility to keep easily in touch with nurses the most, and benefit the best from drawing up a RPP.

Because patients could stay easily in touch with nurses, patients did not have the feeling they had to prevent relapse fully by themselves. They could try to prevent relapse on their own, but always fell back on the PAC-program, and, if necessary, simply be referred to the clinic for more intensive treatment.

I have heard many bad stories about waiting lists. So when I entered the PAC-program, I was glad my patient file was not closed. Thereby, they did not have to put me on a waiting list, if turned out to be necessary (patient 9, age 20).

However, it was still difficult for many patients to submit a support request. They were afraid to ask for help or feared the unknown. It turned out to be important that nurses could be asked for help in an approachable manner, not only via a PAC-meeting, but also by email, phone and even video calls.

In the final stage of treatment, the PAC-program started with drawing up an individual RPP in which triggers, early signs, and actions were described in four stages.

Drawing up a RPP gave patients a clear insight into experiences concerning their eating disorders and the course of previous relapses. Simultaneously with obtaining insight into each stage of relapse, patients internalized their RPP. Thus, the methodological tool helped making implicit knowledge and experience explicit. It was a cognitive strategy to place different stages of relapse in a scheme.

The preparation phase of the PAC-program

Successful application of the PAC-program depended, among other things, on the time at which drawing up a RPP was started. To optimally prevent relapse, patients mentioned to start only once patients are motivated to get better. Beginning too early gave resistance, and made drawing up a RPP feel as a precondition, not as a tool meant to prevent relapse.

According to the Anorexia Relapse Prevention Guideline, the network of the patient should be involved in drawing up a RPP. However, the involvement of the network did not happen in many cases which made it hard to work with this plan at home after it has been drawn up. Patients recommended increasing the involvement of the network more intensively at an earlier stage.

When drawing up a RPP, not everyone was ready to do so, which made it for some patients confrontational. They realized that they were still too ill to participate in the PAC-program. For other patients it was hard to draw up a RPP, because they had to split up relapse in different stages, which was against their nature. Others were bothered by their perfectionism, and remained dissatisfied while describing relapse in detail.

When drawn up different stages of the RPP, I had to write down healthy behavior. I did not have this behavior, but instead anorexic thoughts and behaviors (patient 4, age 21).

The PAC-program in practice

After discharge, the PAC-program continued with working with this plan, both at home and in the clinic through PAC-meetings in which the patient and nurse discuss the condition of the patient.

Although the content of the PAC-meetings was less important than the possibility to keep easily in touch with nurses, as described earlier, the professional expertise of nurses was experienced as a surplus value.

Patients required a good therapeutic relationship to be open and honest about their health status. Therefore patients missed working actively with their RPP during PAC-meetings. They indicated that it would have helped them, not to fool others and/or themselves, but face

their situation. Besides, patients missed to permanently adapt the RPP to their situation, so that the RPP remained up-to-date and useful. Patients did not do this by themselves.

In contrast with limited attention given to the RPP, according to the patients, too much interference was given to weight. Patients wanted to have help for problems not directly related to anorexia nervosa too. Patient mentioned, tackling these problems could also have prevented relapse.

Besides working with the RPP in the clinic through PAC-meetings, patients also worked at home on relapse prevention with the help of social network.

Help of the social network was experienced as supportive when they could count on them. However, concerning social network, patients' advice is to choose someone not too close. Because of the function the network gets, the network can interfere or worry too much, which can result in a disrupted relationship between the patient and their social network, and consequently disturb successful application of the PAC-program.

When it did not go well with me, and I only had my partner, he almost changed in a caregiver ((patient 5, age 28).

If social network also displays psychopathological characteristics, patients did not ask for help of their social network.

I have quite a lot of friends who would love to be thinner. It makes it hard for me to gain weight, when they are concerned about their weight (patient 5, age 28).

In addition to the help patients received from nurses and social network, patients mainly worked independently on relapse prevention.

Within the RPP, a distinction was made between triggers, early signs and actions. The RPP, and therefore also the various components did not work out as intended. Most patients were aware of their early signs. They knew perfectly well when they started the relapse process, and said that they were hardly to be influenced at that point. They also knew what actions could be taken. Mostly they did not make use of the actions described in their RPP, but came up with actions by themselves at that moment. However, patients did not work at all with triggers, while this is particularly important in preventing relapse.

I was no longer thinking about my feelings and thoughts throughout the day as I did in the clinic. Instead, I went back to school. I no longer looked at the RPP, only when I already was too late (patient 8, age 23)

DISCUSSION

This qualitative study attempted to gain a profound insight into the experiences of patients who participated in the PAC-program. This study found patients to be satisfied with the program. They could keep in touch with nurses, and, if turned out to be necessary, go back to the clinic easily. By drawing up a RPP patients got an overview about each stage of relapse. Simultaneously, they internalized the plan in daily life. However, throughout the PAC-program they did not work actively with the RPP anymore. On top of the help from network expertise of nurses was the surplus value. Although the PAC-meetings gave too much attention to anorexia nervosa, instead of others problems related to relapse.

The diverse experiences of patients from the PAC-program could be explained by the different illness levels on which patients started the program. The most helpful part of the PAC-program was drawing up the RPP. Simultaneously, more benefit may be retrieved if worked more actively with the RPP. It looks like patients required help from others (the network and/or nurses) to do so. The borderline, in which the network helps or hinders the patient, looks paper-thin. This might be caused by the relationship they have, which is not a detached patient-nurse relationship. That patients mentioned that nurses have given too much attention to weight, can be interpreted as a good thing. Patients were apparently, at this part, far enough to manage weight by themselves. One of the main goals of the PAC-program.

The PAC-program, in accordance with the Dutch Anorexia Relapse Prevention Guideline, is new. Because this is the first study towards the program, the best option to obtain knowledge about patients' appreciation of the program was to choose a descriptive research design. It is a strength of this study that the researcher, who conducted the interviews, was an outsider. Patients could give their opinion freely about the PAC-program.

Commonly used for sample size estimation in qualitative research is the method of data saturation, sampling until redundancy is achieved and no new information is obtained. In this study, saturation could be achieved with a relatively small sample of ten participants, since participants were able to reflect on their experiences effectively (Polit & Beck 2008). Consequently, findings can be generalized to women with anorexia nervosa who participated in the program during the same period of time. However, interviews with patients' social network are missed to obtain a complete understanding of the experience of the PAC-program.

Although the Dutch Anorexia Relapse Prevention Guideline has been developed for both men and women, only women participated in this study. No men were available for

participation. Consequently, findings of the relapse prevention aftercare program, cannot be generalized to men with anorexia nervosa.

Because some patients received, in addition to the PAC-program, other forms of healthcare, results could be biased. Otherwise, the other forms can be seen as care as usual.

CONCLUSION

The experience of adult patients, who participated in a PAC-program of a specialized eating disorder clinic, after discharge from clinical treatment for anorexia nervosa, is generally perceived as good. Contributed factors of the effectiveness of the aftercare program, sometimes were hindered factors too.

RECOMMENDATIONS

The objective of this study was to adapt the program, on the basis of the obtained knowledge, in such a way that is better tailored to the patients' preferences. Patients have provided valuable recommendations to improve the PAC-program, which must be taken into account. Besides, it must be considered to further implement working with the RPP, so the benefit does not stop once drawn up, but continues at home, and during PAC-meetings.

This study focused on adult patients. However, highest incidence rates, 109 per 100,000 per year, have been demonstrated among 15-19-year-old females (Hoek 2006). The Dutch Anorexia Relapse Prevention Guideline also distinguishes between adults and youth. Although relapse prevention for youth does not differ much from adults, for youth may concerned other research findings. Therefore further research should be done towards this high risk group.

Additionally, no research is done towards men, even though anorexia nervosa also appears in men, only less frequent. It would be interesting to study experiences of men towards the PAC-program, and whether this differs from women.

Finally, the experience of the social network was excluded in this study. However, to adapt the PAC-program in such a way that relapse could be optimally prevented, the experience of the social network also should be known.

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TABELS

Table 1 | Core symptoms of anorexia nervosa (Pike 1998)

- Weight loss below a BMI of 18.5 or below 85% of normal weight;
- Increase in restrictive eating, so that this results in weight loss;
- Increase in behavioral symptoms such as over evaluation of body shape and weight compared to the previous response;
- Absence of menstruation if this had returned during the earlier stage of recovery;
- The occurrence of medical problems associated with the eating disorder.

Table 2 | Baseline characteristics

	Participants (=10)
Age, median	22.4 (21.5)
Gender, <i>n</i> (%)	
Female	10 (100%)
Nationality, <i>n</i> (%)	
Dutch	10 (100%)
Civil status	
Single	6 (60%)
Unmarried partners	2 (20%)
Domestic partnership	2 (20%)
Highest level of education, <i>n</i> (%)	
Medium	5 (50%)
High	5 (50%)
Employment status	
Employed	3 (30%)
Unemployed	7 (70%)
Home ownership	
Living at home	8 (80%)
Living away from home	2 (20%)

Duration of the PAC-program, median	21.2 (22)
Number of PAC-meetings, median	6.3 (5)

SUMMARY

Title: aftercare in patients with anorexia nervosa, a descriptive study.

Background: anorexia nervosa is a serious disease which affects patients' physical, psychological, and social development and functioning (Strober *et al.* 1997). To improve the condition of the patient with anorexia nervosa, treatment should also focus on relapse prevention. The Dutch Anorexia Relapse Prevention Guideline has been developed to work structurally on relapse prevention of patients with anorexia nervosa after discharge.

Aim: this study is designed to gain a profound insight into the experiences of patients who participated in the Periodic Anorexia Check (PAC)-program based on the guideline, as well as insight into factors that contribute to or hinder successful application of the PAC-program.

Methods: a descriptive qualitative research design was chosen to interview ten adults with anorexia nervosa to describe their experience related to a methodological approach aimed at the prevention of relapse in adult patients with anorexia nervosa.

Results: patients were satisfied with the PAC-program because they could easily keep in touch with nurses. By drawing up a relapse prevention plan (RPP), patients internalized the plan in daily life. However, they did not work actively with the RPP during the PAC-program anymore. Patients received help from their social network and nurses. According to them too much attention was given to weight throughout the PAC-program.

Conclusions: the experience of adult patients towards the PAC-program is generally perceived as good, at some points the PAC-program should be improved.

Recommendations: more research is needed towards youth and male patients, and their social network. Patients' recommendations should be taken into account.

Keywords: anorexia nervosa, relapse prevention, aftercare, nurse, adolescents, eating disorder

SAMENVATTING

Titel: nazorg bij patiënten met anorexia nervosa, een beschrijvende studie.

Inleiding: anorexia nervosa is een ernstige ziekte, die de fysieke, psychologische en sociale ontwikkeling en het functioneren van patiënten beïnvloedt (Strober *et al.*, 1997). Om de conditie van de patiënt met anorexia nervosa te verbeteren, moet de behandeling zich ook richten op de preventie van terugval. De Nederlandse Richtlijn Terugvalpreventie Anorexia

Nervosa is ontwikkeld om structureel te werken aan de preventie van terugval van patiënten met anorexia nervosa na ontslag.

Doel: deze studie is ontworpen om een diepgaand inzicht te verkrijgen in de ervaringen van patiënten die deelnamen aan het Anorexia Periodieke Keurings (AKP)-programma gebaseerd op de richtlijn, evenals inzicht in de factoren die bijdragen aan of belemmeren van succesvolle toepassing van het APK-programma.

Methode: een beschrijvend kwalitatief onderzoek is gekozen om tien volwassenen met anorexia nervosa te interviewen om zo hun ervaringen met betrekking tot een methodologische aanpak gericht op het voorkomen van terugval bij volwassen patiënten met anorexia nervosa te kunnen beschrijven.

Resultaten: patiënten waren tevreden met het APK-programma, omdat zij gemakkelijk in contact konden blijven met verpleegkundigen. Met het opstellen van een terugvalpreventieplan (TPP), internaliseerden patiënten het plan in het dagelijks leven. Toch hebben zij niet meer actief gewerkt met het TPP in het APK-programma. De patiënten kregen hulp van hun sociale netwerk en verpleegkundigen. Volgens patiënten hebben deze teveel aandacht besteed aan hun gewicht gedurende het APK-programma.

Conclusie: de ervaring van volwassen patiënten richting het APK-programma wordt over het algemeen als goed beschouwd, op sommige punten dient het APK-programma nog te worden verbeterd.

Aanbevelingen: er is meer onderzoek nodig naar jeugdige en mannelijke patiënten, en hun sociale netwerk. Er moet rekening gehouden worden met de aanbevelingen van patiënten.

Trefwoorden: anorexia nervosa, terugvalpreventie, nazorg, verpleegkundigen, volwassenen, eetstoornis