



The Anorexia Relapse Prevention Guideline in Practice: a case report

Berno van Meijel, Lector GGZ Verpleegkunde

Tamara Berends, Onderzoeker Lectoraat GGZ Verpleegkunde

Annemarie van Elburg, Hoogleraar Klinische Psychopathologie, in het bijzonder eetstoornissen, Universiteit Utrecht

Dit artikel biedt inzicht in de wijze waarop hulpverleners in de geestelijke gezondheidszorg een bijdrage kunnen leveren aan het voorkomen van terugval bij patiënten met de psychiatrische ziekte anorexia nervosa. De auteurs ontwikkelden een praktische richtlijn bestemd voor hulpverleners, patiënten en familieleden om op methodische wijze invulling te geven aan deze terugvalpreventie. Het artikel demonstreert aan de hand van een case studie hoe de richtlijn feitelijk kan worden uitgevoerd. Het artikel is van grote praktische relevantie voor hulpverleners en studenten. Naar schatting 30-50% van de patiënten maakt een terugval in de ziekte door, vandaar dat het gericht aandacht schenken aan het voorkomen ervan hoge prioriteit verdient.

Introduction

Anorexia nervosa is a serious psychiatric disorder which can be defined as a person's refusal to maintain body weight at or above a minimally normal weight for age and height (APA, 2001). Anorexia patients are often extremely underweight, and both their physical and psychosocial functioning are under serious threat as a result of the disorder. Anorexia nervosa predominantly affects girls and young women. The largest group at risk are teenagers aged 15 to 19. The state of the art in the treatment of anorexia nervosa has been documented in various guidelines (The Dutch Committee for the Development of Multidisciplinary Guidelines in Mental Health Care, 2006, and the American Psychiatric Association, 2006). Generally, the focus of treatment is on the patient's eating habits, body weight, and body image, although the impact of psychological problems, such as lack of self-esteem, perfectionism, traumas, as well as problems with fitting into the system or functioning in society, is also given due consideration.

Despite the treatment offered, however, the risk of relapse remains considerable. An estimated 30-50% of all in-patients successfully treated for their eating disorders relapse (Pike, 1998), especially during the first two years after their discharge from the clinic (Strober, Freeman, & Morrell, 1997; Carter, Blackmore, Sutandar-Pinnock, & Woodside, 2004). Carter et al. (2004) conducted a survival analyses among 51 weight restored AN patients and concluded that the risk of relapse is highest from 6 to 17 months after discharge. The risk of relapse diminished with time and reduced to virtually zero after 18 months.

Relapse is defined in this context as the recurrence of a number of diagnostic key symptoms following an initial positive response to treatment (Pike, 1998; Berends, van Meijel, & van Elburg, 2010). The key symptoms in question are:

- (1) Weight loss leading to an BMI below 18.5 or to body weight less than 85% of that expected;
- (2) Tighter food intake restrictions resulting in weight loss;
- (3) Increase in behavioural symptoms such as over-evaluating body weight and body shape;
- (4) Increase in compensatory behaviour, e.g. self-induced vomiting, misuse of laxatives, diuretics, or enemas, binge-eating;
- (5) Cessation or disturbance of menstrual cycles (if restored during the earlier stages of recovery);
- (6) Onset of medical problems connected with the eating disorder, for example, hypotension, bradycardia, hair loss, cold hands and feet, and dizziness.

As is evident from available guidelines, there is general consensus that relapse prevention in the target group of anorexia patients is a matter of essence. Even so, however, there is not much practical information available about how to structure preventative actions in nursing practice. This is why we have developed the Anorexia Relapse Prevention Guidelines, a scientifically based tool for nurses to approach relapse prevention in a structured manner (Berends et al., 2010). This article describes the mechanisms of the Anorexia Relapse Prevention Guideline in the form of a case report. As a preface, the main characteristics of the Guideline will be briefly explained first.

The Anorexia Relapse Prevention Guideline

The Guideline is made up of three parts: (1) a theoretic framework for relapse and relapse prevention, developed on the basis of both the literature and practical experience of experts, including a number of conclusions and recommendations; (2) a practical manual for nurses; and (3) a workbook for patients. The task of the nurses in this context is to use the practical manual and the workbook to draw up a Relapse Prevention Plan in close collaboration with the patient. An overview of the Guideline is provided in table 1.

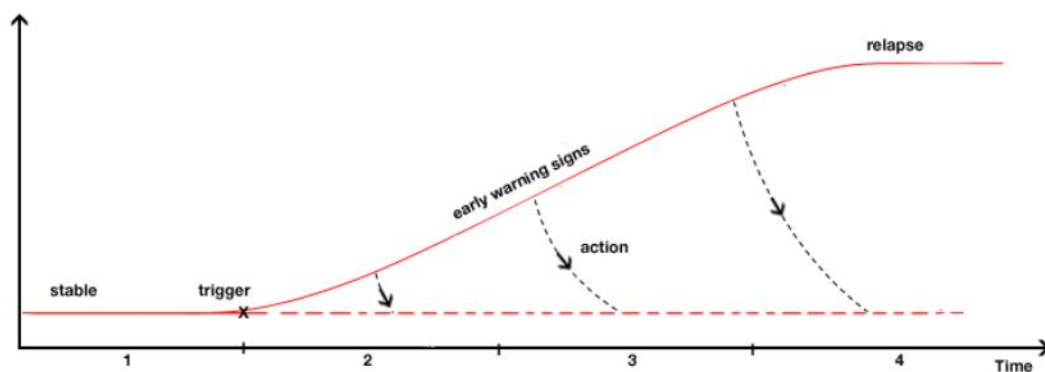
Table 1: Guideline overview

Guideline Overview
<ol style="list-style-type: none"> 1) General information about relapse and relapse prevention 2) Inventory of strengths of the patient 3) Inventory of risk factors 4) Describing potential triggers 5) Describing early warning signs 6) Describing preventive actions 7) Choosing auxiliaries 8) Writing a motivation list 9) Drawing up the Relapse Prevention Plan

An essential aim of the relapse prevention methodology is that nurse, patient and their family work together to gain a better understanding of a patient's individual process of relapse. To achieve that aim, a number of steps must be taken: firstly, a joint evaluation of the relapse *risk factors* that apply; secondly, an inventory of specific factors in everyday life that trigger anorexic thoughts and behaviour (*triggers*) and that may mark the beginning of a process of relapse; thirdly, a detailed specification of individual *early warning signs*, such as feelings, thoughts, behaviour and body signs warning against the onset of a relapse. The essence of the relapse prevention strategy is to ensure that action is taken as early as possible at the recognition of early warning signs. The sooner action is taken, the lower the damage will be and the quicker the patient will recover.

The process can be illustrated as follows in figure 1.

Figure 1: Process of relapse



The process of relapse can be sub-divided into four phases:

- Phase 1:* Stable: the patient is able to maintain a body weight commensurate with her age and height; the patient functions well at home and in society and although the patient may have anorexic thoughts, she does not act upon them;
- Phase 2:* Mild relapse: anorexic thoughts intensify and the patient occasionally shows signs of behaviour indicating the recurrence of the eating disorder, e.g. by occasionally choosing 'safe' products or not eating between-meal snacks.
- Phase 3:* Moderate relapse: anorexic thoughts take the upper hand and the patient increasingly acts on those thoughts by starting to eat less, exercise more, or exhibit purging behaviour (vomiting, use of laxatives); the patient's behaviour is visible to the outside world, to some extent at least, and she starts to lose weight.
- Phase 4:* Full relapse: the patient's body weight drops below 85% of that expected, and she ceases to menstruate; anorexic thoughts dominate the patient continuously, she withdraws from her family and friends, and engages in purging behaviour.

Treatment of AN is a multidisciplinary matter, as is the use of relapse prevention strategies. The nurse who has a close and intensive professional relationship with the patient, is in the most favorable position to work effectively with the patient and her relatives on relapse prevention. However, good coordination and communication with the other members of the multidisciplinary team is of paramount importance.

Drawing up a fully-fledged relapse prevention plan requires approximately 6 meetings between patient and nurse. Initial practical experience with the Guideline showed that individual sessions should last approximately 45 minutes and should preferably be scheduled every other week. After each session, the patients were given homework which they had to make either individually or together with people close to them. The Guideline is suitable for use with inpatients, outpatients, and day-care patients.

Case Report¹

Susan is a young woman of 21 years who has been diagnosed with anorexia nervosa. She lives at home with her parents and a sister. In October 2007, when she was 17, Susan first started to have eating problems. She ate less and began to lose weight. When her mother forbade her to ride her bike to school every day (a distance of 35 kilometres), she started to eat even less in order to achieve the

¹Note: To protect the privacy of the patient, the patient information has been slightly altered in this case report, without this having any effect on the essence of the report.

desired loss of body weight. In December, her general practitioner referred her to a centre for mental health care. After the first intake, the centre informed her that they were unable to treat her for lack of time. Susan's parents eventually took her to a dietician. After 4 sessions, however, her somatic condition had deteriorated to such an extent that the general practitioner referred her to a paediatrician. She was immediately sent to a general hospital for a week in order to be tube-fed. After that, Susan was referred to a specialist clinic for eating disorders.

Having successfully received treatment in the specialist clinic as an inpatient for a period of 5 months plus additional day-care treatment for 8 months, Susan was discharged. Both she and her parents were very satisfied with the treatment program followed.

However, things went wrong during the first summer holiday. Abandonment of the tightly structured eating schedule and a confrontation with unfamiliar foods during the holiday period caused a relapse. Susan lost 5 kilos, and her dread of eating and fear of body gain resurfaced with vigour. Her parents brought Susan back to the specialist clinic for eating disorders, where she was admitted immediately. After a brief period of clinical treatment combined with dietetic counselling and cognitive behavioural therapy, she received follow-up treatment in the clinic's day-care facility. During the latter period, Susan started to work on a relapse prevention plan. It took 6 sessions to complete the plan.

Relapse Prevention Plan

First Session

The first session was attended by Susan and her parents. In order for a relapse prevention plan to be successful, both the patient and her parents (or other parties directly involved) need to be willing and motivated to cooperate. Susan and her parents received information on the risk of relapse and the importance of prevention. They were also shown how a relapse prevention plan could help reduce the risk of relapse.

Specific examples were given to explain to them the principles of early recognition and early intervention. Susan and her parents were then able to recall triggers, early warning signs and helpful interventions from their own experience. Possible ways to intervene that were taught during treatment were discussed and analysed. Susan indicated that distractions, such as writing in her diary, had helped her during difficult times and that she had always found it very comforting when other people assumed responsibility for her eating and exercising patterns and gave her instructions on how to change her behaviour.

The next step during this first session was to identify Susan's strengths. Patients sometimes find it difficult to emphasise their strengths (as opposed to their weaknesses), but the strong points in a patient's personality and functioning are very important to the process of preventing an imminent relapse. The patient's inner power must be fostered to that end. One of Susan's strengths was the ease with which she connected to other people. Another strength was her persistence in achieving her goals. All relevant information collected in this first session was recorded in the workbook, which was given to Susan to take back home.

Second session

The second session was used to work with Susan on identifying all relevant relapse risk factors. Potential risk factors are known from the literature and are regarded as having predictive value (see table 2). A translation of the general risk factors to Susan's specific situation was to contribute to a realistic assessment of her actual exposure to the onset of a relapse. In Susan's workbook, risk factors 1, 3 and 4 were given specific consideration.

Table 2: Relapse risk factors

Potential relapse risk factors
1) <i>Anorexic thoughts about body weight and body image at the time of discharge</i> (Pike, 1998; Carter et al., 2004; Keel et al., 2005; Federici & Kaplan, 2007)
2) <i>Compulsive urge to exercise at the time of discharge</i> (Strober et al., 1997; Carter et al., 2004; Federici & Kaplan, 2007)
3) <i>Prolonged disorder / earlier treatment</i> (Carter et al., 2004)
4) <i>Low psychosocial level of functioning</i> (Keel et al., 2005), <i>which is defined as the inability of a patient to deal with psychosocial stress factors in everyday life.</i>

The next step in the process was to identify and analyse relevant triggers, i.e. factors (usually in the patient's direct environment) which can trigger behaviour typical of an eating disorder and, therefore, increase the risk of a relapse. The origin of Susan's eating disorder and her first relapse were discussed to that end. The following triggering factors were recorded in the workbook: 'going away on holiday', 'loss of structure surrounding daily meals' and 'unfamiliar foreign foods'. In Susan's view, these factors had been mostly responsible for the fact that she had been unable to adhere to her healthy eating patterns. As homework, Susan was asked to look ahead 6 months (together with her parents) and identify the most difficult events that were likely to occur during that period. The idea was that, by looking ahead, Susan would be able to prepare for those situations.

Third Session

The third session started with an evaluation of the homework. Susan had described 3 potential triggers for the next 6 months:

- (1) Independent living: this was a trigger because it meant that she would have to provide for herself;
- (2) Falling ill (influenza): Susan generally went down with flu in the autumn; she did not feel like eating much at such times and immediately lost weight; after recovery, she always had trouble re-establishing a healthy eating pattern;
- (3) Reduced body weight control after treatment: this made Susan insecure because she found it difficult to assess weight stability.

These triggers were noted in the workbook.

After that, the early warning signs were identified and worked out in greater detail. Early warning signs can be described as feelings, thoughts, behaviour, and body signs which precede the onset of a relapse and should accordingly be treated as a warning that a relapse may occur.

In the workbook, 5 categories of early warning signs were distinguished, described in the first person to create 'aha' moments of recognition in the patient:

- (1) Eating pattern (I'm going to throw away my lunch)
- (2) Physical symptoms (My hands and feet are getting cold)
- (3) Exercising (I'll bike really fast when I'm going somewhere)
- (4) Cognition (I worry more and more about how I look and whether others appreciate me)
- (5) Social functioning (I've stopped seeing my friends)

To identify relevant warning signs, Susan was asked to reflect on the beginning of her eating disorder as well as the relapse she had suffered. She experienced this process of reflection as highly confrontational and emotional, which showed how stressful this period had been for her. During these previous episodes she had told many lies about her eating and exercise pattern. This provoked many feelings of guilt. But above all she had felt very sick and weak, with many somatic complaints and depressed mood. These experiences contributed to Susan's strong motivation not to relapse again.

At the end of this session, Susan was instructed to sit with her parents and identify possible other early warning signs. She was also asked to work out all warning signs in greater detail and fit them into the 4 relapse phases described above.

Fourth session

The fourth session again started with an evaluation of the homework. Susan's parents had been able to add a number of other early warning signs. They

described, for example, how Susan tended to cut her bread in tiny pieces and spread the pieces out over her plate when she was in phase 3 of the process of relapse. Susan had been unaware of this fact. The analysis of the early warning signs was successful: Susan was capable of allocating the various warning signs to the different relapse phases.

The remainder of the fourth session was spent on developing possible actions to prevent an imminent relapse. The actions were divided into 2 groups: actions to respond to triggers and actions to respond to early warning signs.

First, the subject of potential triggers was addressed once more. For example, Susan's consistent and immediate response to any comment on her body was to eat less. She was, therefore, asked to think about alternative ways to respond, without relapsing into the eating disorder. How, for instance, did her friends respond in similar situations? All triggers were addressed in this way and appropriate actions were described. Susan discovered that she generally acted in one of the following ways when being confronted with a trigger: (1) find a distraction by going for a stroll, (2) talk to her mother or a friend, (3) write in her diary, or (4) think positively to counter her negative feelings.

Secondly, the subject of early warning signs and possible actions to respond to those signs were discussed in greater detail. One of the issues addressed was that Susan's ability to take responsibility for her own health diminished as the process of relapse evolved. It was important, therefore, that others took over at least some of that responsibility in such situations, and that Susan was offered a tightly structured environment to prevent a further relapse.

The following actions were defined, all of which pertained to her eating pattern:

Phase 1: (stable): I'll stick to a varied diet.

Phase 2: I'll return to a tight structure of meals.

Phase 3: I'll follow the dietician's nutritional advice to the letter.

Phase 4: I'll eat under the supervision of my parents, or one of them.

All actions were noted in the workbook.

After all possible actions were defined, a search was launched for "auxiliaries", people who would be able to help Susan recognise triggers, early warning signs and prevent a relapse through early intervention. The availability of "auxiliaries" was essential because Susan tended to rely solely on herself in finding solutions to her problems. She had learned from the past that it was very difficult for her to admit to herself or to others that she was having problems. Together with Susan, efforts were made to recruit both 'active' and 'passive' auxiliaries. *Active auxiliaries* were people she felt close to and people whom she could comfortably turn to for

help and support. Active support was marked by a two-way communication system: Susan could take the initiative in seeking help, but active auxiliaries would also be permitted to confront Susan with her eating patterns whenever they observed increased symptoms of the eating disorder. *Passive auxiliaries* were people whom Susan could approach if she needed support or, in other words, who would be there when Susan needed them. In Susan's case, her mother was listed as an active auxiliary and her father as a passive auxiliary. Susan preferred not to involve outside people: she knew no other adult person who she felt was close enough to support her as a formal auxiliary; and she did not want to discuss the relapse prevention plan with her friends. To them, she wanted to be 'normal Susan'.

At the end of the fourth session, after all items of the relapse prevention plan had been addressed, Susan's motivation to make use of the plan in future was given special attention. Potential setbacks were identified and analysed with a view to ensuring adherence to the relapse prevention plan in such adverse situations. In addition, emphasis was placed on the positive effects of having control over the eating disorder. Susan was asked to describe those positive effects as detailed as possible in the workbook. A few of the positive effects mentioned were: (1) the chance to enrol in a new study programme; (2) the ability to go out with friends without being inhibited by the eating disorder; and (3) healthy exercising.

Fifth session

In the fifth session, all items and issues discussed and worked out were combined into one encompassing relapse prevention plan. Such a plan generally consists of only 1 page on which all triggers are listed, as well as the early warning signs by phase and the proposed response actions. See table 3 for more details on Susan's relapse prevention plan. Specific agreements were made about the method of implementation, the persons to be involved, and the tasks to be assigned to each person.

Sixth session

The sixth and final session was a joint meeting between the nurse, Susan, and her parents to discuss all details of the relapse prevention plan once again and document the responsibilities expected of all people involved. This feedback process proved to be very difficult to Susan, as she was asked to be completely open about many aspects of her eating disorder which she had kept hidden from her family and friends until then. Susan's parents stated that the clear actions described in the plan might give them a good foothold to overcome obstacles. They felt that they now had a tool to intervene and prevent a serious relapse, especially at times when Susan denied having a relapse, out of embarrassment or fear.

Table 3: Relapse Prevention Plan

Relapse Prevention Plan

Triggers:

- Falling ill (influenza)
- Going away on holiday, no meal structure, unfamiliar foods
- Moving into rooms
- (Negative) comments on how I look
- Death of a friend or family member

Actions:

- Find a distraction by going for a stroll
- Talk to my mother or a friend
- Write in my diary
- Think positively to counter negative feelings

Phases	Description of situation / early warning signs	Actions
Phase 1 (stable)	I listen for signs of hunger, but that's not easy, so I follow the dietician's nutritional advice. I feel dizzy sometimes, but that may also be because of my low blood pressure. I occasionally have negative thoughts about myself, and my parents sometimes criticise my eating pattern.	<ul style="list-style-type: none"> - Make schedule to weigh in - Find a distraction - Think positively to counter negative thoughts - Talk to parents about points of criticism - Stick to a varied diet
Phase 2	I increasingly tend to reach for 'easy' sandwich toppings, like jam and smoke-dried beef, and want to eat lower-calorie food. I put thinner layers of toppings on my sandwiches and keep rigidly to meal times. No between-meal snacks. I bike ever faster. I lose weight, which stops my menstrual cycle. I get tired more rapidly. Negative thoughts about myself increase, and discussions with my parents about eating become more heated.	<ul style="list-style-type: none"> - Go back to nutritional advice and a varied diet - Make schedule to weigh in - Lower level of activity - Write in diary to let thoughts go - Go for a stroll, talk to a friend - Use relapse prevention plan!
Phase 3	I start to eat slower and cut my food into pieces and spread them out over my plate. I leave out (some of) my between-meal snacks. I lose more weight; I get cold more rapidly and find it hard to warm up again. My energy levels drop and negative thoughts about taking in food increase. I am absent-minded more often.	<ul style="list-style-type: none"> - Go back to nutritional advice - Eat in the presence of one of my parents - Dress warmly when cold - Make schedule to weigh in - Call general practitioner - Reduce activity levels and stop exercising - Discuss thoughts with parents (auxiliaries) - Inform friends about eating problems and ask for their support
Phase 4 (crisis)	I'm constantly counting calories and want to eat as little as possible. This means that I eat toast and leave out butter/gravy, sometimes skipping entire meals. As my body weight drops, I start to grow downy hair, my finger nails stop growing, and I become ill more rapidly. My knees wobble, I move robot-like and I start to talk monotonously. My relations with friends become more superficial. I'm often absent-minded, live in a world of my own, and stare aimlessly.	<ul style="list-style-type: none"> - My parents take over responsibility for my food intake - Dress warmer - Weigh more often at fixed times - Call the clinic - Interrupt study due to illness - Discuss thoughts with nurse / counsellor

Follow-up

After completion of the relapse prevention plan, Susan was placed in an after-care programme. She was invited to follow-up meetings, with fairly long intervals, in order to assess her situation on the basis of the relapse prevention plan. The first follow-up meeting took place after 3 months. Susan told that everything went well and that she had been able to maintain a stable body weight. She and her mother had sat down to discuss her situation every two weeks. At first, it had been difficult to talk about the relapse prevention plan. Susan's mother had not really known what questions to ask, and Susan had found it difficult to be open as she was afraid that her mother would start to check on her again. However, as they continued their talks, they had gradually established a relationship of trust and improved their communication with each other.

The relapse prevention plan was re-evaluated and adjusted on some points on the basis of recent experiences. Again, potentially stressful situations arising in the nearby future were taken into consideration, including the start of her new study programme, which she dreaded and regarded as a possible trigger for a relapse. It was agreed that she should strictly adhere to mealtimes and food quantities during the relevant weeks. This procedure should be sufficient for Susan to prepare for the months ahead of her.

Discussion

The purpose of this case report is to illustrate how the Relapse Prevention Guideline can be used in nursing practice. Working with this Guideline has proven to have a number of advantages, not only for the patient, but also for her parents and the nurse. The Guideline provides an effective tool for relapse prevention: they ease the suffering of both the patient and her parents; they are conducive to the patients' psychosocial recovery process; and they contribute to the cost-effectiveness of treatment and care. Furthermore, the Guideline encourages open communication during the process of writing the relapse prevention plan, which helps the patient to accept her own situation. Matters pertaining to the eating disorder are deliberately made explicit, which makes it impossible for patients to continue their strategy of denial and also helps them cope with the feelings of sorrow and loss that are inherent in persons who suffer from a very serious eating disorder. By working on relapse prevention, patients no longer feel that a relapse is something that just befalls them. They gain a better understanding of the relapse process, and that enables them to change the course of the process and move towards recovery. The active involvement of the patient and her parents also improves the patient's capability of self management and enhances communications between the patient and her parents. The relapse prevention plan allocates clear tasks to the various parties involved and defines where the responsibility of the patient and each of her parents and counsellors begins or ends. This, in turn, provides reassurance and reduces the level of (over)protectiveness of the parents.

Implications for Nursing Practice

For anorexia counselling nurses, the Guideline offers a way to give effect to a well-structured professional procedure which is expected to yield a clear health benefit for the patient. The Guideline fills an obvious gap in nursing practice: although it is clear from both the literature and nursing practice that relapse prevention in anorexia patients is of the essence, our previously conducted literature review during the preparation stage of guideline development revealed no structured relapse prevention methods for patients with anorexia nervosa. Because of their close and intensive professional relationship with the anorexia patients, nurses are in a very good position to work with anorexia patients on establishing a relapse prevention plan.

One of the essential conditions for an effective use of the Guideline is that the patient must be intrinsically motivated to prevent any future relapse. Consequently, the patient's motivation should be evaluated regularly in order to determine whether measures must be taken to boost that inner motivation. Nurses should take precautions to ensure at all times that their reliance on a patient's motivation is firmly based on reality. Use of the Guideline requires specific skills: motivating patients and removing resistance are activities that demand advanced nursing competencies. Only nurses who have built up ample working experience with the target group are sufficiently skilled in providing good nursing care and avoiding the pitfalls of socially desirable responding. Moreover, use of the Guideline presupposes a great deal of methodical and analytical skills. All of this means that additional training will be necessary for nurses to make effective use of the Guideline.

It is evident from practical experience that the Guideline are highly suitable as a tool to work with anorexia patient on the prevention of potential relapses, but further scientific research will be required to establish the effectiveness of that tool.

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Eerder verschenen

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