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ORIGINAL ARTICLE

Relapse prevention in anorexia nervosa: Experiences of patients and parents

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ABSTRACT: *One of the main aims of treatment after successful recovery from anorexia nervosa (AN) is to prevent a relapse. The Guideline Relapse Prevention (GRP) Anorexia Nervosa offers a structured approach to relapse prevention. This study explores how patients and their parents experience working with the guideline. It also describes the factors that support or hinder successful application of the guideline. A descriptive qualitative research design was chosen involving in-depth interviews with seventeen patients with anorexia nervosa and six sets of parents. Patients and family members were generally satisfied with the support provided by the GRP. It contributed significantly to a better understanding of the personal process of relapse. Patients and families valued being able to keep in touch with their professional during the aftercare programme. The GRP supports the patient's use of self-management strategies for relapse prevention.*

KEY WORDS: *anorexia nervosa, patient's perspective, relapse intervention, relapse prevention, self-management.*

INTRODUCTION

Anorexia nervosa (AN) is a severe mental illness with an estimated lifetime prevalence among women of 2% (Keski-Rahkonen *et al.* 2007; Smink *et al.* 2012) and high mortality rates of 5% per decade (Marcellus *et al.* 2011; Smink *et al.* 2012). Relapse is common among AN patients who previously showed full remission. In international studies with varying follow-up periods, the relapse rates range from 30% to 57% (Carter *et al.* 2004, 2012; Eckert *et al.* 1995; Herzog *et al.* 1999; Keel *et al.* 2005; McFarlane *et al.* 2008; Richard *et al.* 2005; Strober *et al.* 1997; Walsh *et al.* 2006).

Leading guidelines in the field of eating disorders (American Psychiatric Association, 2006; Dutch Committee for the Development of Multidisciplinary Guidelines in Mental Health Care, 2006; NICE Clinical Guideline, 2004) generally agree that relapse prevention is crucial for patients with AN. One major problem, however, is the lack of methodological

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support in implementing relapse prevention strategies in practice. We have addressed this issue by developing the Guideline Relapse Prevention (GRP) Anorexia Nervosa, an evidence-based tool for health professionals and patients that offers a structured approach to applying relapse prevention strategies (Berends *et al.* 2010). One of the main aims of this guideline is to improve the self-management skills of patients and family members with regard to their illness, in particular relapse prevention. The five core self-management skills described by Lorig & Holman (2003) are interwoven into the guideline: problem-solving, decision-making, resource utilization, forming of a patient/healthcare provider partnership, and taking action.

The GRP has been implemented in a specialized treatment centre for eating disorders in the Netherlands. A recent study (Berends *et al.* 2016) carried out in this setting among 83 participants showed that the rate of full relapse was 11% ($n = 9$) and the rate of partial relapse 19% ($n = 16$), with patients returning to full recovery within three months. Seventy per cent ($n = 58$) did not relapse. The above rate of full relapse is much lower than in other studies (Carter *et al.* 2004, 2012; McFarlane *et al.* 2008), indicating that the GRP offers a promising form of intervention for reducing relapse in this patient group.

The aim of this study was to understand how patients and parents experience working with the GRP, in particular the use of self-management strategies for relapse prevention. The study also aims to identify facilitators and barriers for applying this guideline successfully.

METHOD

Design

The researchers selected a descriptive qualitative research design, based on thematic analysis (Braun & Clarke 2006), using semi-structured interviews to gain an in-depth understanding of how anorexia nervosa patients and their parents experienced working with the GRP Anorexia Nervosa. Thematic analysis is an appropriate research design, as it aims to identify relevant themes derived from the experience of patients and parents, also referring to barriers and facilitators when using the Guideline. The study protocol was approved by the Institutional Review Board of the institution and the Medical Ethical Committee (protocol number: 12-424/C).

The Guideline Relapse Prevention Anorexia Nervosa

To prevent relapse, the health professional, the patient, and her family collaborate closely on gaining a better understanding of the patient's individual relapse process. Working together, they analyse and describe in detail the triggers and early warning signs of relapse, broken down into four stages: stage 1) the patient is stable and functioning well; stage 2) mild relapse, anorexic thoughts intensify, and the patient occasionally shows signs of behaviour indicating the recurrence of the eating disorder; stage 3) moderate relapse, anorexic thoughts take the upper hand, and the patient increasingly acts on those thoughts; and stage 4) full relapse, anorexic thoughts dominate the patient continuously, and the weight drops below 85% of that expected. They also identify the actions to be carried out in the event of an impending relapse. This information is summarized in an individual relapse prevention plan (RPP). The content of the RPP is based on patients' and family members' experiences with previous relapses, as well as insights concerning relapse and the risk of relapse gained during treatment. Once preparation of the RPP has been completed in the final stage of treatment, the patient is ready to start the aftercare programme. In our specialized treatment setting, the aftercare programme is referred to as the periodic anorexia check (PAC) programme. It is a low-frequency aftercare programme lasting at least 18 months. During PAC meetings, the patient's condition is closely monitored and discussed at length making use of the RPP.

The frequency of the PAC meetings depends on the patient's condition and the need for treatment and care. For example, patients who are stable will attend a PAC meeting after 4–6 months. Less stable patients may attend PAC meetings every 2 months. After 18 months, the patient and the health professional can decide to extend the aftercare period for a maximum of 5 years if there is a prolonged vulnerability to relapse (Berends *et al.* 2010). PAC meetings last 45 min and are attended by the patient and, if relevant, a family member. The patient is weighed, and her condition is evaluated at each meeting. During the visit, two main topics are discussed: the patient's psychological and social functioning (overall mood, school, friends, sports, etc.) and the presence of AN symptoms (anorectic cognitions, abnormal eating habits, excessive exercise pattern, etc.). Between formal PAC meetings,

the patient or a family member may contact the health professional at any time if help is needed. The patient's record contains the following information about each PAC meeting: weight, possible stage of relapse, and arrangements made during the visit. For an overview of the guideline, see Table 1. For a complete description of how the guideline is applied, see the case report by Berends *et al.* (2012). The guideline is freely accessible via the Internet (www.relapse-an.com).

Setting and participants

This study was carried out in a specialized treatment centre for eating disorders in the Netherlands. The treatment provided in this setting is based on the state-of-the-art recommendations made in three sets of guidelines: the Dutch Multidisciplinary Guideline for Eating Disorders (2006), the NICE Guidelines for Eating Disorders (2004), and the American Psychiatric Association Practice Guideline: Treatment of Patients with Eating Disorders (2006). Treatment focuses on three areas: (i) eating habits, body weight, and body image; (ii) psychological aspects of functioning, such as self-esteem, perfectionism, and traumas; and (iii) social functioning within the family system and in society.

To qualify for inclusion in this study, participants had to meet the following criteria: aged 12 or older; successfully completion of treatment, with weight restored to a normal (SD) BMI based on their age and height; in possession of a relapse prevention plan at the start of the aftercare programme; participation in the aftercare programme for at least 18 months.

Study participants were selected in two stages. The adult participants (age > 18 years) were selected between the latter part of 2011 and the early part of 2012. The adolescents (age 12–18 years) and their parents were selected during a second round in spring 2013.

Twenty-two participants were eligible to participate, that is 14 adults and eight adolescents. Two participants refused to participate without giving any reason. Three others refused because they did not want to discuss their illness history again. Seventeen participants were included in our sample, ten adults with a mean age of 22.5 (range: 19–32), and seven adolescents with a mean age of 16.6 (range: 14–18). The mean BMI (kg/m^2) at the start of the treatment was 16.1 (SD: 1.74); at the start of the PAC programme, it was 19.7 (SD: 1.33). The mean BMI at the end of the aftercare programme was 19.5 (SD: 1.71). The mean length of participation in the PAC programme was 20.6 months (SD: 5.32). The mean number of PAC meetings was 5.4 (SD: 3.26). Three participants experienced a full relapse during the aftercare programme, and six participants experienced a partial relapse. Six sets of parents participated in the study.

Data collection and analysis

Data collection took place by means of semi-structured interviews. To prepare for the interview, the researchers extracted the course of illness over the past 18 months of the PAC programme from the participants' files. The researchers also produced a summary of the discussion between the health professional and the participant at every PAC meeting.

An interview protocol was constructed based on the structure of the GRP and focusing on the different components of the relapse prevention plans: the preparatory stage; identification of triggers and early signs of relapse; formulation of actions to prevent further relapse; and help by family members. The interview further involved evaluating the contribution of the health professionals and the usefulness of the PAC meetings. This meant exploring how the participants and their families experienced all these topics as well as perceived barriers to and facilitators for effective implementation and execution of the relapse prevention programme.

The interviews with the participants lasted ~90 min and the interviews with the parents ~30 min. The interviews took place at a location of the participant's choice and were recorded on audiotape, with the participant's permission. Audio-taped interviews were transcribed verbatim. Data analysis involved generating a category scheme with related code words, based on the structure of the GRP and the derived topic list. To ensure the highest possible coding consistency across the interviews, the two primary researchers coded the entire data set. Because they did not expect the definition of predetermined code words to bias subsequent data collection and analysis, they constructed a code tree in advance based on the structure of the GRP (Hsieh & Shannon 2005). This initial code tree was adjusted during the process of data analysis.

Thematic analysis was performed to identify meaningful themes in the interview material. Thematic analysis involves the following six phases: (i) familiarization with data, (ii) generating initial codes, (iii) searching for themes among codes, (iv) reviewing themes, (v) defining and naming themes, and (vi) producing the final report. The software program NVivo 10 was used

TABLE 1: *An overview of the Guideline Relapse Prevention Anorexia Nervosa*

Step 1	Psycho-education to patient and relatives about relapse and relapse prevention.	For example: Education about how the use of a relapse prevention plan could help to reduce the risk of relapse
Step 2	Identification of the patient's strengths with respect to personality and functioning.	For example: The patient has excellent skills to connect with other people, or the patient is persistent in achieving her goals.
Step 3	Identification of risk factors for relapse.	For example: Previous research shows that having difficulties in coping with stress is a risk factor for relapse.
Step 4	Identification of potential triggers for relapse.	For example: Loss of structure and confrontation with foreign foods when going on vacation.
Step 5	Identification of early warning signs which precedes the onset of a relapse.	For example: 1. Eating pattern: 'I throw away my lunch and therefore I miss one meal'. 2. Physical symptoms: 'My hands and feet constantly feel 3. Exercising: 'I bike really fast when I'm going somewhere. And I don't feel well during biking'. 4. Cognition: 'I worry more and more about how I look and whether others appreciate me'. 5. Social functioning: 'I stop visiting my friends'.
Step 6	Describing preventive actions, responding to triggers and early warning signs.	For example: Actions in response to triggers: 1. 'Going for a stroll to clear my mind and relax'. 2. 'Talking to my parents or a friend to express my feelings'. 3. 'Writing in my diary'. Action for early warning signs: 1. Eating pattern: 'I'll return to a tight structure of meals'. 2. Physical symptoms: 'I'll dress warmer when I feel cold'. 3. Exercising: 'I'll bike together with friends in order to slow down the speed'. 4. Cognition: 'I'll think positively to counter negative feelings'. 5. Social functioning: 'I'll push myself to keep visiting my friends'. cold'.
Step 7	Choosing informal caregivers (parents, relatives, friends) who support the patient in using the relapse prevention plan.	For example: '1. My mother, because she sees me every day and I can talk to her. 2. My swimming coach, because she was the first to find out about my eating disorder and she can help me monitor my sport activities'.
Step 8	Identification of motivating factors for the patient when working with the relapse prevention plan.	For example: 'Stability regarding my eating disorder increases the chance to enroll in a new study program'. 'The ability to go out with friends without being inhibited by the eating disorder'.
Step 9	Drawing up the final relapse prevention plan with the information from steps 1 to 8.	
Step 10	Start of the aftercare programme during a minimum of 18 months.	Two scenarios can occur during these meetings: (1) The patient is stable, in which case the focus is on maintaining this stable condition by promoting good physical health and optimal personal and social functioning. Actual or possible stressful life events in the near future are discussed and anticipated on. (2) The patient shows one or more early signs of impending relapse, in which case the main focus during the visit is on obtaining a thorough understanding of the actual triggers of relapse and how to deal with these in order to promote recovery. In this context, specific arrangements are made and actions are planned, based on the content of the previously established relapse prevention plan.

to support data analysis. For a further elaboration of these phases, we refer to Braun and Clarke (2006).

Research quality

Two interviewers listened objectively and critically to the tape-recorded interviews to improve the quality of subsequent interviews (Polit & Beck 2008). The research team discussed four of the interviews to evaluate the interview structure and techniques. To evaluate and enhance the reliability of the data analysis process, the two primary researchers kept a log of decision points. The research team discussed the log to check the accuracy of the coded data and the implications for describing the findings (Creswell 2007; Polit & Beck 2008). To obtain feedback on their individual interpretations during data analysis, the researchers presented their final results to a multidisciplinary peer

review panel consisting of three professors (mental health nursing and psychiatry), one senior researcher, and five psychologists in training.

RESULTS

The following three sections describe the experiences of the participants and parents who were interviewed, including the factors that they identified as facilitators and barriers for implementing the GRP.

General evaluation

Applying the GRP involves drawing up a relapse prevention plan (RPP) and working with this plan at home. Regular PAC meetings are meant to evaluate the process of working with the RPP, including systematic monitoring of early signs and symptoms of relapse. Participants and parents stated during the interviews that they were generally satisfied with the GRP. Participants on average gave the GRP a score of 7.4 (range: 5–8.5) and parents a score of 7.5 (range: 7–8) (1 = extremely poor; 6 = sufficient; 10 = excellent). Participants mentioned that drawing up a relapse prevention plan contributed significantly to their understanding of their individual relapse process. Participants and parents valued the fact that they could keep in touch with their health professional during the PAC programme; it felt like a safety line to them.

> With the PAC program, you know that you won't just be put out on the street after your treatment. It feels like you have a safety line to your own health professional. That really felt secure. (Participant 5, age 28)

> The most important point for us as parents was to have someone to fall back on when things were not going well. The relationship with the health professional, that back-up, gave us the confidence to let go. (Parents 2)

Because participants and parents could stay in touch with the health professionals during the PAC programme, they were able to get support in maintaining their balance and preventing a relapse. They experimented with personal relapse prevention strategies on their own, but could always fall back on the health professionals from the PAC programme for support, and, if necessary, simply be referred to the treatment centre 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. And they would not have to put me on a waiting list, if it turned out to be necessary. (Participant 9, age 20)

It was important to participants and parents to have easy access to the health professionals, not only at scheduled PAC meetings, but also on an *ad hoc* basis by e-mail, phone, and video calls.

The participant, their family members, and the health professional decided together on the frequency of the PAC meetings, so the schedule could be tailored to the participant's preferences and needs. With the focus on self-management, a balance was sought between activities that could be employed independently or with minimal coaching on the one hand, and activities that needed more intensive support on the other hand. This individualized approach made a positive contribution to the smooth transfer from intensive treatment to the low-frequency PAC programme. Despite this generally positive appreciation of the programme, a frequently mentioned barrier was that participants were not eager to come to PAC meetings in the eating disorder centre, because it meant being confronted with other patients who were still ill and recalling their own period of severe mental illness. However, the perceived need to actively work on relapse prevention prevailed and the confrontations did not prevent the participants from coming to the PAC meetings.

> I just didn't want to think back to the time I was ill. I just wanted to be normal and go my own way, but I knew that the PAC meetings were important to attend and the contact with my health professional were pleasurable. (Participant 11, age 16)

The preparatory phase

At the start of the PAC programme, that is in the final stage of treatment just before discharge, the participant started by drawing up an individual RPP describing triggers, early warning signs of relapse, and actions to be taken in the event of impending relapse in four successive stages. Drawing up an RPP gave participants a clearer understanding of their personal experience of their eating disorder and the course of previous relapses. It helped make implicit knowledge explicit. Entering the different stages of relapse into a diagram was a cognitive strategy.

> It really helped me to visualize my eating disorder, as well as my own stages of relapse. To know when there's a risk of severe relapse and how to act when this happens. Previously I was aware of certain signals, but thought they weren't important. But if you look at

> them at a deeper level, they are definitely relapse triggers. It's nice to understand myself better so I can intervene more quickly. (Participant 8, age 23)

Simultaneously, as they came to understand their relapse process better, participants were able to internalize the content of their RPP, making them less dependent on their detailed plan and giving them more opportunities to use the RPP content in everyday situations. Participants regarded drawing up an RPP as an important step, although it was not always easy to do. They found it confrontational to think back to the start of their eating disorder because it was a stressful period in their life. Participants were inclined to avoid thinking about periods of severe mental distress. They seemed to find it particularly difficult to further elaborate the early signs of relapse in different relapse stages, although feelings of satisfaction were often present after completing the task.

> The early signs were vaguely present in my mind, and sometimes a little chaotic. It is quite confronting thinking about the past and the unpleasant time during my illness. I didn't want to think back really. But when you write down the early signs, it becomes clear what they actually mean. When I was finished, I found it enlightening. (Participant 7, age 18)

However, some participants were troubled by perfectionism and remained dissatisfied when describing their process of relapse in detail. They also found it difficult to make time for it at home, as it is a time-consuming activity. Despite the perceived barriers, drawing up the RPP was experienced as an essential step to obtain a better insight into the process of relapse.

The GRP recommends that the participant's network be actively involved in drawing up the RPP. In the case of the adolescents, parents were commonly involved in decision-making throughout the whole treatment, and so the younger participants did actively involve their parents in drawing up the RPP. In the case of the adult participants, however, their networks often did not become actively involved, making it hard for them to work with the plan at home with the help of network members. Participants often felt ashamed to ask for help or were convinced they should be able to do it by themselves, which was the main reason for them to keep their network members at a distance. Despite this restraint, the participants frequently ask the health professionals to support them involving their network in relapse prevention activities, both in the preparatory stage and the implementation stage.

Successful participation in the aftercare programme depended in part on how the process of drawing up the RPP was timed in terms of the patient's motivation to work actively on her recovery and on preventing relapses. Starting the relapse prevention strategies at the right moment, that is when the patient was relatively stable and felt ready to end treatment, contributed to the patient's self-confidence and provided opportunities to gain more self-awareness. The change from intensive treatment to the PAC programme, with opportunities for personalized care, was experienced as smooth and felt secure.

> I liked to move on and I felt more and more that I was doing well and was sufficiently stable. It was nice to work on the RPP to complete my treatment. (Participant 5, age 28)

> I learned to know myself better by drawing up the RPP and that gave me confidence, I knew I would be able to do it on my own. (Participant 11, age 16)

Starting the relapse prevention strategies too soon, that is when the patient was still in intensive treatment, was confrontational and demoralizing for some participants because it made them realize that they were still too ill to participate in the aftercare programme.

> When I was drawing up the different stages of the RPP, I had to write down healthy behavior that I could show. But I was not able to show this behavior, because my anorexic thoughts and behaviors were still predominant. (Participant 4, age 21)

The GRP in practice

Once a participant had completed the RPP, she embarked on the stage of actively working with the plan within the context of the PAC programme. It was especially important to participants to have easy access to health professionals if their situation deteriorated. Participants required competent health professionals with specialized knowledge and expertise concerning all the different aspects of the eating disorder. They further emphasized the value of a good therapeutic relationship with this health professional, one in which they could be open and honest about their health status.

> I felt at ease with my health professional, that's why I dared to talk about subjects I was ashamed of and which I found very difficult to talk about. (Participant 7, age 18)

> My health professional played an important role during my treatment. During the PAC visit she focused on

> subjects that were really important to me. I only wanted to talk about everyday situations, but my health professional put emphasis on situations that were challenging to me, my real weaknesses and difficulties.
>
> (Participant 4, age 21)

During the PAC visit, two main topics were discussed: the patient's psychological and social functioning (overall mood, functioning at school, relationships with friends, sports, etc.) and the presence of AN symptoms (anorectic cognitions, abnormal eating habits, excessive exercise pattern, etc.). When discussing these topics, both strengths and weaknesses of the participant could be explored, and opportunities to increase self-management skills were searched for. Despite the availability of easily accessible support, however, it was seemingly difficult for many participants to actually ask for this support when needed. They were hesitant and sometimes afraid to ask for help, or they feared the unknown.

> It is very hard, I think I always try to avoid asking for help, so I don't need to think about the eating disorder that is playing up again. I go out with friends more, work harder, just make sure I have a busy schedule. When I think about it, then I tend to avoid it and find it very hard to ask for help. You know, you have to admit that it is not going well, and I was afraid, even though they are really professional, that they wouldn't take me seriously. I was afraid they wouldn't understand me. (Participant 5, age 28)

The majority of the participants indicated that they did not work with the RPP actively during the aftercare period. They gave different reasons. For example, some said that it all went so well that the RPP was not of real value at that particular time. Others were convinced that they could manage their mental health status without explicit use of the RPP, so they put it away instead of keeping it in sight. Another common reason was that the participant had largely internalized the content of the RPP, so she was familiar with the plan and there was no need to use the detailed version.

> It is not literally the plan that plays an important part when a relapse is starting, but the thoughts and ideas I have written down in the plan that are useful. Those are integrated into the strategy I have and use every day of my life. I don't think that physically sitting down with the plan would help. (Participant 1, age 19)

Participants sometimes felt that they had failed if they used the plan actively in their daily life. They demanded of themselves that they could apply preventive strategies without using the RPP actively. They explained that the high standards they set for themselves played a significant role in this. Another crucial barrier to using the RPP actively was that some health professionals did not use the plan explicitly during the PAC meetings. As a result, the RPP faded into the background and new knowledge concerning the course of the disorder and use of self-management strategies was not integrated into the plan.

> What I missed was using the RPP during the PAC meetings. I don't like the confrontation, but if we had used the RPP more actively, it might have been easier for me to admit that I was showing stage 2 or maybe even stage 3 signs of relapse. And what's difficult is that, because it wasn't used, it isn't up-to-date, it won't grow with your situation that way.
>
> (Participant 4, age 21)

The respondents indicated that it would have helped them to make more active use of the RPP so as to avoid fooling others and/or themselves, and instead face their personal situation and the threat to their mental health status.

Some of the participants also used the RPP to work on relapse prevention at home, with the help of their social network. In the majority of the cases, their families were very helpful and played an important role in applying relapse prevention strategies, for example by talking to the participant when things were not going well and by asking questions that gave the participant a better understanding of their dysfunctional eating or exercise patterns. Family members provided support in hard times and often were able to correct the participants in their (pre-)anorectic behaviours. They also supported the participant by just being there and by listening without judging. Their support could also be very practical in nature, for example checking the participant's eating pattern.

> My stepmother is very good at helping me, she can calm me down. She shows me the world isn't going to crumble beneath me. She helps keep me on my feet. Just by talking and asking questions, and when I answer honestly it helps me understand my own behavior. (Participant 6, age 19)

> Every Sunday evening, we sit down together with our daughter for about 15 minutes. Just to talk about how the week went, and to talk through the list of triggers from the relapse prevention plan. Then we know exactly how our daughter is doing, and whether we could maybe help out in some way. (Parents 4)

In other cases, their network members were not actively involved. Some participants felt that their family members were too emotionally involved, so that they worried too much, grew critical when the participant's situation deteriorated, or interfered too much with the participant's eating pattern. Participants experienced this as oppressive, leading them not to involve family members in working with the RPP.

> Checking up on me and getting angry and that kind of thing really only backfires. It makes me angry, depressed and I eat even less. Talking and listening, that helps, not becoming angry. (Participant 8, age 23)

For these participants, the PAC visit were even more important to obtain the necessary support, because they could not turn to their own network when they needed help, among other things with respect to the use of relapse prevention strategies.

DISCUSSION

The GRP is used by the participant, her family members, and health professionals to obtain a better understanding of the process of relapse, thus increasing opportunities to intervene at an early stage of deterioration. Participants and family members gave different explanations for how the guideline helped improve self-management skills. The five core self-management skills described in the introduction (Lorig & Holman 2003) can also be found in the interviewees' statements. (i) Drawing up the RPP improves problem-solving skills, encouraging the participant to focus on finding adequate responses to everyday problems and the exacerbation of symptoms. (ii) Decision-making: using the RPP and by internalizing its content, participants become more capable of making effective decisions regarding the challenges they are experiencing in relation to their eating disorder and a possible relapse. (iii) Resource utilization: the RPP explicitly encourages participants to use external resources, for example make use of the support of their social network or parents and – if needed – seek professional help at the earliest possible stage during the overall aftercare programme. (iv) Forming of a patient–healthcare provider partnership: this is a core element of the GRP, that is working collaboratively towards the same goal of relapse prevention. Participants need to build a relationship of trust with the health professional, with quick access to professional support in the event of an impending relapse. In partnership, participant and professional caregiver can learn from previous and current experiences and events. (v) Taking action: the predetermined actions formulated in the RPP means the participant is prepared to take effective action in the event of destabilization. The improvement in self-management skills reduces the participant's dependence on health professionals or members of her social network.

These findings are in line with Keel *et al.* (2005), who found that poor psychosocial functioning and support of women with AN are a predictor of relapse. These women may be less equipped to cope with life stressors that could possibly influence the recurrence of symptoms. Working with the GRP within a good therapeutic relationship may contribute to the development of effective coping strategies to better deal with these psychosocial stressors that influence the recurrence of relapse.

Regarding the participant's social network, the interviews showed that this network can play either a helping or hindering role with respect to relapse prevention. This can be explained to a large extent by the nature of the relationship between the participant and family members. When the relationship was more detached and family members were supportive and took a noncritical attitude, they were better able to help the participant through the process of recovery and relapse prevention in particular. By contrast, when family members were emotionally involved and had a critical attitude towards the participant's behaviour, the participant could experience their presence as stressful and thus not helpful for further recovery and relapse prevention. These findings are in line with previous research findings concerning the concept of expressed emotion (EE), which also applies to patients with eating disorders (Butzlaff & Hooley 1998). Involving the social network in the process of relapse prevention is essential, but the timing and selection of the right person(s) are important. During their aftercare visits, health professionals are advised to explore whether this relationship is positive and supportive and will thus contribute to relapse prevention. If it is not, psycho-education and coaching should be part of the aftercare intervention programme to help the family member engage in more effective interaction with the patient.

The interviews revealed that use of the RPP during PAC meetings was inadequate in a number of cases. To ensure that the plan remains up to date and that the patient makes active use of it in her daily life, it is vital to discuss the RPP during PAC meetings and update it in line with recent experiences. During these meetings, the health professional should encourage

patients to keep the RPP up to date and to discuss the RPP with their network.

Strengths and limitations

Studies on relapse prevention are scarce. Little is known about predictors of relapse, and no evidence-based relapse prevention strategies are available. There is clearly a need for more research on relapse and on relapse prevention strategies (Carter *et al.* 2012; Keel *et al.* 2005; Khalsa *et al.* 2017; Richard *et al.* 2005). This is the first qualitative study on how patients and their families experience the use of a structured relapse prevention strategy derived from evidence and practice-based guidelines. This research design allowed us to gain an in-depth understanding of the patients' and family members' experiences and their opinion of the guideline. One of the strengths of this study is that the researchers, who conducted the interviews, were not employed in the specialized setting themselves, thus increasing the objectivity of the qualitative research process. Participants and parents were free to describe their experiences and express their opinions about working with the GRP, and they valued the anonymity. In addition, an external researcher (BM) provided the main supervision for the study, as described in the method section.

The study achieved data saturation with a relatively small sample of seventeen participants because the participants were able to reflect on their experiences effectively. Once the 23 interviews had been conducted, no new essential information was added. Another strength of this study is that it investigated the perspectives of both adolescent patients and parents concurrently. Unfortunately, interviews with the adult participants' social network were not included, which is a weakness. In future research, the social network of the adult patients should also be included to gain a complete understanding of how patients experience working with the GRP.

CONCLUSION

The purpose of this study was to gain a deeper understanding of the experiences of AN patients and their families when applying the Guideline Relapse Prevention (GRP). Our conclusion is that participants and parents were generally satisfied with the support provided by the GRP. The plan gave them significant help in understanding their own relapse process. Most participants had internalized the content of the RPP in such a way that they relied on the plan less and could apply self-management strategies successfully. Participants and parents valued the fact that they could keep in touch with their health professional during the aftercare programme; it felt like a safety line to them.

RELEVANCE FOR CLINICAL PRACTICE

When the GRP is applied in practice, it is essential to allow for variation between participants. Most participants were motivated to work with the GRP, and they were open about their vulnerability to possible relapse. They actively sought contact with their family or health professionals when they relapsed or felt at risk of doing so. Others, however, found it difficult and confrontational to work with the GRP and had a more avoidance coping style. Alongside these differences in attitude and context, factors such as intelligence level, cognitive skills, and insight into the illness must also be taken into account. At the individual level, these variables interact in a complex manner, requiring the relapse prevention strategies to be tailored to the individual characteristics and context of the patient.

It is evident from this qualitative study, but also from previous quantitative research into the preliminary effects of the GRP (Berends *et al.* 2016), that the guideline is a highly suitable tool for working with anorexia nervosa patients on preventing potential relapses. Future experimental and cost-effectiveness research will be required to improve and further establish the effectiveness of this guideline.

REFERENCES

American Psychiatric Association (2006). *Practice Guideline: Treatment of patients with eating disorders*. Washington, D.C.: APA.

Berends, T., van Meijel, B. & van Elburg, A. (2010). *Richtlijn Terugvalpreventie Anorexia Nervosa (Guideline Relapse Prevention Anorexia Nervosa)*. Assen: Koninklijke Van Gorcum.

Berends, T., van Meijel, B. & van Elburg, A. (2012). The Anorexia Relapse Prevention Guidelines in practice: A case report. *Perspectives in Psychiatric Care*, *48*, 149–155.

Berends, T., van Meijel, B., Nugteren, W. *et al.* (2016). Rate, timing and predictors of relapse in patients with anorexia nervosa following a relapse prevention program: A cohort study. *BMC Psychiatry*, *16*, 316.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 93.

Butzlaff, R. L. & Hooley, J. M. (1998). Expressed emotion and psychiatric relapse: A meta-analysis. *Archives of General Psychiatry*, *55*, 547–552.

Carter, J. C., Blackmore, E., Sutandar-Pinnock, K. & Woodside, D. B. (2004). Relapse in anorexia nervosa: A survival analysis. *Psychological Medicine*, *34*, 671–679.

Carter, J. C., Mercer-Lynn, K. B., Norwood, S. J. *et al.* (2012). A prospective study of predictors of relapse in anorexia nervosa: Implications for relapse prevention. *Psychiatry Research*, *200*, 518–523.

Creswell, J. W. (2007). *Quality Inquiry and Research Design: Choosing among Five Approaches*. London: Sage Publications Inc.

Dutch Committee for the Development of Multidisciplinary Guidelines in Mental Health Care (2006). *Multidisciplinary Guidelines Eating Disorders*. Utrecht: Trimbos Institute.

Eckert, E. D., Halmi, K. A., Marche, P., Grove, W. & Crosby, R. (1995). Ten-year follow-up of anorexia nervosa: Clinical course and outcome. *Psychological Medicine*, *1*, 143–156.

Herzog, D. B., Dorer, D. J., Keel, P. K. *et al.*, *et al.* (1999). Recovery and relapse in anorexia and bulimia nervosa: A 7.5-year follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, *38*, 829–837.

Hsieh, H. F. & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*, 1277–1288.

Keel, P. K., Darer, D. J., Franco, D. L., Jackson, S. C. & Herzog, D. B. (2005). Postremission predictors of relapse in women with eating disorders. *American Journal of Psychiatry*, *162*, 2263–2268.

Keski-Rahkonen, A., Hoek, H. W., Susser, E. S. *et al.* (2007). Epidemiology and course of anorexia nervosa in the community. *American Journal of Psychiatry*, *164*, 1259–1265.

Khalsa, S. S., Portnoff, L. C., McCurdy-McKinnon, D. & Feusner, J. D. (2017). What happens after treatment? A systematic review of relapse, remission and recovery in anorexia nervosa. *Journal of Eating Disorders*, *5*, 20.

Lorig, K. R. & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, *26*, 1–7.

Marcellus, J., Mitchell, A. J., Wales, J. & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry*, *68*, 724–731.

McFarlane, T., Olmsted, M. P. & Trotter, K. (2008). Timing and prediction of relapse in a transdiagnostic eating disorder sample. *International Journal of Eating Disorders*, *41*, 587–593.

NICE Clinical Guideline (2004). *Eating disorders. Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders* [Cited 2 November 2016]. Available from URL: www.nice.org.uk/cg9

Polit, D. F. & Beck, C. T. (2008). *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. New York, NY: Lippincott Williams & Wilkins, a Wolters Kluwer Business.

Richard, M., Bauer, S. & Kordy, H. (2005). Relapse in anorexia and bulimia nervosa—A 2.5-year follow up study. *European Eating Disorders Review*, *13*, 180–190.

Smink, F. R. E., van Hoeken, D. & Hoek, H. W. (2012). Epidemiology of eating disorders: Incidence, prevalence and mortality rates. *Current Psychiatry Reports*, *14*, 406–414.

Strober, M., Freeman, R. & Morrell, W. (1997). The long-term course of severe anorexia nervosa in adolescents: Survival analysis of recovery, relapse, and outcome predictors over 10–15 years in a prospective study. *International Journal of Eating Disorders*, *22*, 339–360.

Walsh, B. T., Kaplan, A. S., Attia, E. *et al.* (2006). Fluoxetine after weight restoration in anorexia nervosa: A randomized controlled trial. *Journal of the American Medical Association*, *295*, 2605–2612.