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RUNNING HEAD: FOUR PATHWAYS TO ANOREXIA NERVOSA

ABSTRACT

Introduction: Studies show that patients' perception of their illness has a direct influence both on their utilization of health services and their adherence to treatment plans. This may be particularly relevant to the treatment of Anorexia Nervosa (AN). Previous studies on AN have typically explored single psycho-social factors that patients with AN relate to the emergence of their illness. There is a need for more coherent systematic descriptions of the complexity of the patients' narratives about how their illness emerged. In this study we sought to identify common components in the participants' narratives. By identifying different combinations of these components in the narratives, we sought to describe differences in patients' perceived pathways to AN.

Methods: Participants were 36 women aged 18 – 51 years who had been treated for AN within the past two years at five clinical institutions in Norway. Semi-open qualitative interviews were conducted, tape-recorded, transcribed and analysed using grounded theory techniques.

Results: We identified the following four distinct perceived pathways into AN: "The Avoidant", "The Achiever", "The Transformer", and "The Punisher". The pathways could be regarded as four different projects for mastering life's challenges.

Discussion: Our results suggest that there seem to be at least four pathways into AN. This indicates that a common array of symptoms might cover very different psychological dynamics. These might need to be treated therapeutically in different ways and should probably be taken into account during the refinement of diagnostic tools.

Key Practitioner Message:

- Although patients with AN might present similar symptoms, patients' perspectives on the emergence of their problems indicate that a common array of symptoms cover a variety of subjective psychological dynamics.
- From the experienced patient's stance, there are at least four distinct pathways to the emergence of AN.
- Attempts to master the challenges of life were found to be a common denominator in the emergence of AN.

- Recognition and integration of the patient's understanding of her or his problems should be given high priority in treatment of AN.

INTRODUCTION

Anorexia Nervosa (AN) is a serious illness (Klump, Bulik, Kaye, Treasure & Tyson, 2009) that leads to more deaths among young women than any other mental illness (Sullivan, 1995). Currently, there is a lack of evidence for recommending the use of one treatment over another (Bulik, Berkman, Brownley, Sedway & Lohr, 2007; Fairburn, 2005). Patients tend to come late into treatment (Rosenvinge & Klusmeier, 2000), frequently drop out of treatment (Wallier, Vibert, Berthoz, Huas, Hubert & Godart, 2009), and the treatment situation is challenging both to patients (Higbed, 2010) and health care personnel (Warren, Crowley, Olivardia & Schoen, 2009). In trying to understand the dynamics of these patients' treatment motivation and help-seeking behaviour, in-depth studies of the patients' own experiences have been shown to be a valuable – and probably underutilized – source of knowledge. Previously, we have used patients' experiences to explore the meaning of self-starvation (Nordbo, Espeset, Gulliksen, Skårderud & Holte, 2006), the link between negative emotions and eating disorder behaviour (Espeset, Gulliksen, Nordbø, Skårderud & Holte, 2012), body image distortion (Espeset, Nordbø, Gulliksen, Skårderud, Geller & Holte, 2011; Espeset, Gulliksen, Nordbø, Skårderud & Holte, 2012), preferred therapist characteristics (Gulliksen, Espeset, Nordbø, Skårderud, Geller & Holte, 2012), and the patients' wish to – or reluctance to – recover from AN (Nordbø, Gulliksen, Espeset, Skårderud, Geller & Holte, 2008; Nordbø, Espeset, Gulliksen, Skårderud, Geller & Holte, 2012). In the present study we use in depth study of AN-patients' experience to systematically explore patients' perception of how their illness emerged. It is widely accepted that the causes of AN are complex and multifactorial (Striegel-Moore & Bulik, 2007; Polivy & Herman, 2002). In this study we aim to identify some of the overarching lines in this complexity, as seen from the patient's point of view.

A wide range of illness studies show that patients' perception of their illness has a direct influence both on their utilization of health services and their adherence to treatment plans (Petrie & Weinman, 2012). Beliefs about causes, consequences, identities, timelines and controls/cures (Leventhal, Brissette & Leventhal, 2003) seem to help the individual to both make sense of her or his experience and to develop an appropriate coping response (Leventhal, Nerenz & Steele, 1984). Some research suggests that how patients view their

illness might play a bigger part in determining their health outcome than does the actual severity of the illness (Petrie & Weinman, 2012).

The patients' perspective on how their illness emerged might be particularly relevant to the treatment of AN. Patients with AN frequently deny that they are ill (Treasure & Schmidt, 2001; Vandereycken, 2006), and tend to attribute positive meanings to their symptoms on a highly personal level (Nordbø et al., 2006; Serpell, Treasure, Teasdale & Sullivan, 1999). Furthermore, they often strongly resent the feeling of being "treated by the book" and they recommend that treatment should be grounded on acceptance of their own perceptions of how their problems emerged (Gulliksen et al., 2012). Ignorance or neglect of these patients' perceptions might therefore inhibit the establishment of a trustful and sustaining therapeutic working alliance and lead to non-compliance.

Previous studies have shown that patients with AN attribute their illness to a number of psycho-social factors (Holliday, Wall, Treasure & Weinman, 2005; Marcos, Cantero, Escobar & Acosta, 2007; Koruth, Nevison & Schwannauer, 2012) including low self-esteem (Holliday *et al.,* 2005; Marcos *et al.,* 2007), personality (Holliday *et al.,* 2005; Marcos *et al.,* 2007; Nilsson, Abrahamsson, Torbiornsson & Hägglöf, 2007), personal behaviour (Marcos *et al.,* 2007), need to be perfect (Marcos *et al.,* 2007; Nilsson *et al.,* 2007), stress (Higbed, 2010), interpersonal problems (Nevonen & Broberg, 2000), weight-related problems (Nevonen & Broberg, 2000), dieting behaviour (Nevonen & Broberg, 2000), family dysfunction (Nilsson *et al.,* 2007; Beresin, Gordon & Herzog, 1989; Tozzi, Sullivan, Fear, McKenzie & Bulik, 2003), and socio-cultural stressors outside the family (Nilsson et al., 2007). While the aim of some of these studies was primarily to detect potential risk factors for AN (Nilsson *et al.,* 2007; Nevonen & Broberg, 2000), others have tried to identify significant subjective experiences (Koruth *et al.,* 2012). Detection of such single psycho-social factors might contribute pieces to the puzzle of understanding patients' illness development. However, in order to meet patients in a way that adequately recognizes their perceptions of how their illness emerged, we also need more coherent systematic descriptions that address the complexity of these patients' narratives.

We have conducted in-depth interviews in which we asked patients with AN to reflect upon, describe in detail and explain how they perceive the emergence of their illness. In this regard, we have primarily been interested in studying patients who have lived with the disorder for some time. There are three reasons for this. First, awareness of AN seems to develop over time (Koruth *et al.,* 2012; Schoen, Lee, Skow, Greenberg, Bell & Wiese, 2012).

In the first phase of the illness, patients seem to restrict their awareness of the greater context of the development of their disorder, and to focus more on details and events in their immediate environment (Koruth *et al.,* 2012). Second, patients who have lived with the disorder for some time, might be expected to have established more reflective and stable narratives that include a wider understanding of the possible relationship between their eating disorder and the context in which the disorder emerged. Third, because AN in many cases develops into a long-lasting disorder (Steinhausen, 1991), the most frequently seen patients in clinical practice are patients who have lived with the disorder for some time (Rosenvinge & Klusmeier, 2000; Newton, Robinson & Hartley, 1993).

Our aim was to identify possible common structural components in the participants' narratives about how their AN emerged that could be used to describe possible differences between their stories.

METHOD

Participants

The participants included 36 women aged 18 – 51 years (mean age 27.3 years) treated for AN (American Psychiatric Association, 1994) within the past two years at five clinical institutions in Norway. At the time of the interview, 10 of the participants were inpatients, and 26 were outpatients. Sample size was defined by criteria of data saturation according to Strauss and Corbin (Corbin & Strauss, 2008); new participants were included until three subsequent interviews had been conducted without any essential new information being added. When 36 participants were interviewed, the criteria of data saturation were fulfilled. All 36 informants had within the past two years been diagnosed with AN (American Psychiatric Association, 1994) by psychiatrist or clinical psychologist specialized in the treatment of eating disorders. At the time of the interview 29 participants fully satisfied the criteria of AN (American Psychiatric Association, 1994). Due to intensive inpatient treatment 7 of the participants had reached a weight within the normal range (BMI > 20). Twentytwo participants were diagnosed with the restrictive type of AN, while 14 participants were diagnosed with the binge-purge subtype of AN. Twenty participants viewed themselves as being in recovery and had recently made changes in their eating disorder behavior. Sixteen participants reported few changes and a more negative view of the future. Information about BMI at the time of the interview was lacking for three participants. The mean reported lowest body mass index

(BMI) while having AN was 13.6 (range 8-17) and the mean time period in treatment was 5.3 years (range 0.5 -14 years).

Setting and procedure

Participants were recruited from various clinical settings where they were either in treatment, post-treatment follow-up or rehabilitation from AN. All participants were informed orally about the study and were invited to participate by their therapist. This was accompanied by a written invitation to participate that contained a detailed description of the purposes and procedures of the research project. After consenting to participate, the participants were contacted by the interviewer. The information about the project was again repeated when the interview started. No participants withdrew from the project after having consented to give their contact information to the researchers.

The interviews were conducted by one of the first three authors (KSG, RHSN or EMSE). The authors had no relationship to the treatment institutions. Each interview lasted between 90 and 120 minutes and was audiotaped and transcribed verbatim. All procedures were conducted in accordance with the Helsinki Declaration, and the study was approved by the Norwegian Regional Committee for Medical Research Ethics.

The aim of the interviews was to provide descriptions as precise and as close to the participants' subjective experience as possible. Accordingly, a descriptive study design was used and principles of grounded theory (Corbin & Strauss, 2008) were followed for the collection and analysis of the data. The data were collected using the "Experience Interview" (Holte, 2000), a semi-open, participant-centered, strategic conversation format developed from communication theory (Littlejohn, 1999). The interviews were initiated with an open question such as, "In your own words, can you tell me how your illness emerged?" To facilitate the interviewee's own development of their themes, the interviewer responded mainly by means of open instructions ("Tell me more…"), references to her own impressions ("How sad!"), and frequent use of verbal ("Really!") and nonverbal (nodding) facilitators. Questions were worded either as open ("What happened?") or limited to elicit specific information ("Did you?").

Data analysis

Analysis of the transcribed interviews was conducted following the guidelines of grounded theory (Corbin & Strauss, 2008). To facilitate the organization of data, the qualitative research

software program QSR-NVivo (Fraser, 1999) was used in the analysis of the interviews. Each text was explored using open thematic coding (Corbin & Strauss, 2008) according to the "bottom-up principle". In this process, all text excerpts that included statements about the emergence of AN were coded into the database and labeled according to their content of meaning. For example, the text excerpt "I matured early, which I just couldn't handle" was labeled "Puberty". All the coded material was then compared, grouped and lifted into higher-order constructs. For example, the code "Puberty" was sorted under the higher-order construct "Triggers". Each higher-order construct was then defined with reference to the content of meaning of all the relevant text excerpts coded under the same construct. The definitions were continuously adjusted as the analysis developed. This coding resulted in four higher-order constructs: "precursors", "triggers", "self-determination", and "reinforcers", which described different structural components in the participants' narratives about the emergence of AN. To arrive at these final constructs, the constructs that had been generated through the open coding were validated against the original text using confirmatory and selective coding (Corbin & Strauss, 2008). The purpose of this backward translation was to ensure that the generated constructs fit with the original text, to detect possible overlap between them and to determine whether further refinements were needed.

Because our aim was to grasp the complexity of the participants' narratives, not just single factors, we also conducted axial coding (Corbin & Strauss, 2008). While the open coding refers to the deconstruction of data (i.e. breaking data apart), axial coding refers to the reconstruction of data. In this process, our aim was to explore how the different higher-order constructs – precursors, triggers, self-determination and reinforcers - were related to each other. In the analysis, experiences from the higher order constructs were combined into four developmental constructs representing the least number of constructs needed to describe how patients perceive their pathway into AN. The four types of pathways were labelled, "The Avoidant", "The Achiever", "The Transformer" and "The Punisher". This coding provided a theoretical model that described individual variation in the participants' narratives in terms of both precursors, triggers, self-determination and reinforcers. In this final analysis, we also explored whether a common thematic denominator for the four types of pathways could be identified (excluding denominators that were directly tied to eating and thinness). In this process, we identified four main life struggles in their narratives that the participants linked to the emergence of their illness. Hence, the analysis was finalized by induction of the central

theoretical concept - "sense of mastery" – that represents the common denominator in the model of the four types of pathways (Corbin & Strauss, 2008).

To illustrate the complexity of the participants' narratives, the four types of pathways have been illustrated by vignettes based on condensed quotations from the interviews. These have been reconstructed into coherent narratives that include all of the structural components. To arrive at the final composition of the pathways and to make sure that they were distinctly different, the four pathways were subjected to thorough comparisons with each other. To ensure that each of the pathways fit with the original texts, the data were analysed a third time according to the "top-down-principle". In this process, each pathway was checked against the original text, to determine whether further refinements were needed to adequately represent the original data and to minimize overlap.

The first two authors (KSG and RHSN) conducted both the open thematic coding and the axial analysis. The correspondence between the coders was high and deviations were corrected through discussion. To add further credibility to the results and to ensure that the concepts were well represented in the data, the analysis process was regularly discussed within the research team and continuously monitored by the last author (AH). This allowed for a transparent research process whereby concepts and interpretations were continuously challenged, discussed and reassessed.

RESULTS

The comprehensive analysis of the 36 narratives identified four common *structural components* that could be organized into a time frame. Based on combinations of variation within these components, we were able to extract four constructs representing four *types of pathways* into AN. Finally, after excluding themes that were directly linked to eating and thinness, we found one *common thematic denominator* across the four types of pathways, which we labeled "sense of mastery".

Structural components

The four structural components were: "precursors", "triggers", "self-determination" and "reinforcers". The four components were all addressed in all of the narratives but their content and appearance within each component varied to a large degree between narratives.

Precursors

Precursors were conditions reported to be present before the participants developed their eating disorder and that the participants considered in their narratives to be important factors in their development of AN. The narratives contained a variety of types of such precursors, including personal characteristics, socio-emotional precursors, body related precursors, cognitive precursors, and precursors linked to role-model affinities. Coded as "Personality characteristics" were "Perfectionism" (*"I have never been satisfied with things being sort of 'halfway'. They should be perfect."*), "Other-orientation" *("I have always been sort of concerned about everyone around me and taken great responsibility for my family"*), "Eating style" (*"Ever since childhood, I have not eaten, or eaten too much, when things have been difficult"),* and "Low self-esteem" *("I felt that I was worthless, and always had low self-confidence"*). Coded as "Socio-emotional precursors" were "Loneliness" ("*I felt lonely the whole time I was growing up"*), "Sadness" (*As long as I can remember, I have had a certain feeling of sadness inside*) "Having few friends" (*"I didn't have very many friends"*) "Anxiety in childhood" (*"I had anxiety and compulsive thoughts throughout my childhood"*) and "Wish to die" (*I couldn't care less, if I had disappeared from the face of the earth).* Coded as "Body-related precursors" were "Hatred towards own body" (*"I hated my body from the time I was six years old"*), "Light body type" (*"I have always gotten a lot of attention because I was thin. I think it all comes back to that"*), and "Heavy body type" (*"I was always taller and weighed more than my classmates"*). Coded as "Cognitive precursors" were "Internalized idealization of thinness" (*"I have always thought that to be thin is to be successful"*) and "Worries about weight and food from an early age" (*"This food and body thing, not getting fat, has occupied me a lot since elementary school"*). Coded as precursors linked to "Role-model affinities" were being "Exposed to dieting among family members (*"All of the adults in my childhood were on diets"*) and "Girls at the gym or in the dance class being openly engaged in eating disordered behaviour" (*"Many of the older girls in my dance class had eating disorders. It influenced me"*).

Triggers

Triggers were distinctive events that were linked in the participants' narratives to the onset of the eating disorder, e.g. "*Issues about food and weight had always been bothering me since my early years* (precursor), *but it was first when my boyfriend broke up and my dog died at*

the same time, that it happened and I lost it completely" (trigger). We found that triggers could be either internal or external.

External triggers

"External triggers" were events originated from the participant's surroundings. We identified six external triggers: "Negative comments on body or weight" (*"A good friend of mine came up from behind and said – Damn, you've really gained weight!"*), "Loss of boyfriend" (*"It started out when I had a boyfriend, and then we broke up"*), "Family conflict" (*"The situation at home with my family was incredibly difficult"*), "Rape" (*"It started with a rape when I was 12 years old. That's when the first thoughts of hating my body started"*), "Parents divorcing" (*"The problems started when my parents divorced"*), and "Loss of family member" (*"My grandmother died, and she was the one family member I had a close friendship with"*).

Internal triggers

Internal triggers were events that originated from within the participant's body and mind. We identified the following four types of internal triggers: "Puberty" ("*I matured early, which I just couldn't handle"*), "Weight gain" (*"My weight was suddenly quite normal and I wasn't particularly thin anymore, which I disliked"*), "Feelings of lack of success" (*"I felt like a total failure in every way"*), and "Intensive exercising" (*"I started up on a really extreme exercise program"*).

Reinforcers

By reinforcers we refer to the content of externally or internally originated experiences the participants' linked to the development and maintenance of their anorectic behaviour. We found two types of reinforcers: external and internal. In self-determination theory (SDT) (Deci & Ryan, 2000; Vansteenkiste, Soenens & Vandereycken, 2005) behaviour are found to be either "controlled" or "autonomously" motivated or reinforced. "Controlled" motivation includes "external motivation" (expectations, rewards and punishment administered by the patients' environment) and "introjected motivation" (guilt, shame, anxiety and internal compulsion). "Autonomous" motivation includes "identified motivation" (personal values and commitment) and "intrinsic motivation" (enjoyment, pleasure and interest). Autonomously – preferably intrinsically motivated behaviour are found to be most likely to be maintained, due to is's high degree of self-determination. The external reinforcers described in this research

are in line with descriptions of controlled motivation labelled external motivation; the patients engage in eating disorder behaviour due to experiencing reactions from others as rewarding. The internal reinforcers described in this research may be understood as autonomously motivated behaviour, of the type "intrinsically motivated behaviour.". The internal or intrinsic reinforcers seemed to play a more prominent role in the development and maintenance of anorectic behaviour than the external reinforcers.

External reinforcers

External reinforcers were events originating from outside of the participant's internal thinking and could be considered "something others do to the person". We identified two types of external reinforcers, "Positive comments on weight loss" (*"When others began to comment that I had gotten skinnier and had a better looking body, it gave me a boost"*) and the "Reduced expectations from others" (*"Suddenly, people were more understanding, and no longer expected me to do my very best"*).

Internal reinforcers

Internal reinforcers were reinforcements that originated from within the participant and could be considered "something persons do to themselves". We identified the following six internal reinforcers: "Sense of achievement" (*"Losing weight was something I could really manage"*), "Autonomy" (*"To abstain from eating was something that was entirely my own decision, something that was totally my own"*), "Feeling high" (*"You get a kick out of not eating. It's like getting high"*), "Feeling less lonely" (*"Suddenly it was me and my eating disorder"*), "Feeling less anxious" (*"My anxiety let go"*), and "Feeling comforted by engaging in anorectic behaviour" (*"When I don't eat, it comforts me in a way"*).

Awareness of self-determination

By awareness of self-determination we refer to the degree of which the participants' were aware of how the external or internal reinforcers motivated their anorectic behaviour. As described above, the reinforcers differed in the degree of motivational or reinforcing "power". Importantly, however, besides differing in the degree of reinforcing or motivational power, the participants' narratives differ in the degree of awareness of the reinforcing power of the external or internal/intrinsic reinforcers. In some narratives the anorectic behaviour was being pursued with a relatively high level of awareness of the reinforcing effect of the behaviour:

"I decided to go on a diet. I was sure it would make me feel better".

"By concentrating on what to eat and what not to eat, I was able to gain a sense of control again".

In other narratives, the participants became aware of the positive effects of their anorectic symptoms much later in their illness development. Rather than actively using their anorectic behaviour to seek inner or external reinforcement, these participants seemed more slowly and coincidentally to become aware of the reinforcing effect of their behaviour – often only after they had started to severely restrict their eating or had become pathologically thin:

"Coincidentally, I started to eat less, like the other girls in my class who were always dieting, to try to fit in. I didn't have any desire to be thinner. But as time went on, I noticed that I felt less sad and unhappy when I didn't eat very much, so I wanted to keep doing this".

Four perceived pathways to AN

Based on different combinations of the variation within the common structural components described above, we identified the following four perceived pathways into AN: The Avoidant, The Achiever, The Transformer and The Punisher. In the following section each type of pathway is illustrated by a prototypical vignette based on condensed quotations from one or several participants that led to the inference of that particular pathway. Information that could reveal a participant's identity has been removed.

The Avoidant

The Avoidant pathway typically contained references to strong precursors related to eating habits, such as pickiness, that occurred in combination with shyness and loneliness and a preoccupation with others' possible negative opinions about the participant. The narratives of these pathways contained only modest references to distinct events that could be considered to be triggers for the eating disorder. Instead, The Avoidant pathway involved the participant claiming to have lived with their problems as long as they could remember ("I have always been that way", "I more or less grew up with it – AN has been a part of my life for as long as I can remember"), and to have slid into AN with a very low awareness of self-determination. The narratives of these pathways were characterized by how the participant accidentally discovered that starving themselves reduced their loneliness, sadness, other negative

emotions, or more unspecific body sensations without any conscious or determined wish to lose weight.

Throughout my childhood, I have always been very thin and a very picky eater. I was, I guess, very determined not to mix food. I had to eat everything separately. I suppose I had some, not that I thought I was fat or that I had to lose weight or anything like that, but I had some strange food habits (Precursor – Eating habits). *And I remember feeling as early as in elementary school, I think, that I was very cautious. I felt like an outsider, and I had some problems making contact with people. I had contact with some people from time to time, but then for example, I didn't dare to ask anyone if they would sit with me because I was afraid they would say "no". I remember that, even back then. I feel sort of a little bit boring and dumb. I can't quite manage to be myself when I am together with someone and eat normally, then that ... (sighs) ... feeling becomes stronger. Then I feel dumb and boring and that people are tired of me – and things like that* (Precursor – Loneliness). *So maybe I've always had a certain ... sadness ... maybe more than others, which I've always known ... that somehow or another could develop into something else* (Precursor – Sadness). *I have thought that this is something not everyone has, and I have struggled a little against that sadness getting bigger, in a way. There were so many feelings that ... I sort of didn't have anywhere to put ... so ... then I guess it became a natural thing, in a way, to find some antidote or ... to not have to think and feel so much. If I'm very stressed out, and there are lots of thoughts and feelings, I have a tendency to eat less. And it actually works very well, because ... things calm down in a way. I can remember feeling it long before I actually developed eating disorders. I discovered as a child how going to bed with an empty stomach made me feel comforted in a way, the feeling of hunger felt comforting to me* (Reinforcer – Feeling comforted by engaging in anorectic behaviour).

The Achiever

The Achiever pathway typically contained references to a distinct time of onset (*"It began the last autumn of high school"*) and one or a combination of distinct triggers (*"The problems were triggered one year ago when a lot of things happened at the same time. It was too much to deal with", "I have always been very thin, but then I gained weight and couldn't handle that"*). The narratives of The Achiever pathway also contained clear references to precursors. However, these were not typically linked to food intake, shyness and loneliness as in the case of The Avoidant pathway. Rather, the predisposing factors in The Achiever pathways were

about perfectionism, conscientiousness and multi-mastery (*" I have always been a perfectionist. I had been very active in music and sports and almost everything, and as time went on it got to be too much"*), often in combination with extreme other-orientation (*"I was very concerned about the opinions of others"*) and low self-esteem (*"I have never felt good enough and always had a low self-esteem").*

In The Achiever type of pathway the development and maintenance of anorectic behaviour was a <u>voluntary project</u> with a high degree of awareness of self-determination. The narratives of this type of pathway contained a history of being very successful in a wide range of activities that at some point became too much or at some point faded somewhat by experiencing a lower level of success (*"Yes, it started when I was 13-14 years old. I had always been one who had mastered everything and had been the center of attention, been good at handball, soccer, and slalom skiing. Couldn't handle coming in second place. It got to be too much for me to be best at everything. Then I found my thing (AN)"*). The multi-mastery was then substituted by mono-mastery – in which the participant sought to master the activity of losing weight and staying thin.

I have always been a person who has mastered everything and been at the center of attention. I was cheerful and happy, involved in everything, was good at everything. I was a good flute player. Good skier. Good student … And finally, I guess during high school, I felt maybe that I didn't quite cope, that I didn't manage to be best at everything anymore (Precursor – Perfectionism). *At the same time people didn't know anything about how I was on the inside. I was very controlled by external factors. So it may have appeared to others that everything was going very well. And I was also very determined to make things work well within my family, although I was not feeling very well on the inside. Because I didn't know myself* (Precursor – Other-oriented). *And then came exams, and they didn't go as well as I wanted, and my body was restless all the time. Felt like chaos around me and within me all the time* (Trigger – Feelings of lack of success). *And then it was sort of like, OK, now I don't have control over anything, so at least I am going to control my body. And then it started when mom and dad went away for three weeks at Easter vacation. Then I stopped eating for those three weeks, and then afterwards everything went back to normal again, but it wasn't anyway, so then the eating disorder had begun, in a way. So I think that was when I found my thing. Like I said, there are a lot of branches on my tree that led to it turning out the way it did. But*

I think that the main reason that it went as far as it did, was that I always felt a need to be perfect, and so I had to find my own little thing that I was best at (Precursor – Perfectionism). *Retreating, all this business with food and so on. It became something very concrete to be occupied with. There, I could win. Be in control. Diet. Yes! So there was darned well nobody that could beat me, you see … then others could be better than me, but I had one thing that I was best at. Nobody was going to beat me at that* (Reinforcer – Sense of achievement). *And the worse I got, the more worried people around me became. The more I had that yes-feeling, that I can manage this better and better* (Reinforcer – Others' comments).

The Transformer

The Transformer pathway typically contained references to precursors consisting of experiences of being mainly unsuccessful due to feeling overweight, experiencing academic problems, or feeling socially unadjusted (*"I have struggled a lot through my childhood with low self-confidence. I did not thrive").* Like The Avoidant pathway, the narratives of The Transformer pathways contained only modest references to distinct events that could be considered triggers for the eating disorder. Similar to The Achiever pathway, The Transformer pathways were characterized by the development and maintenance of anorectic behaviour as a voluntary project with a high degree of awareness of self-determination. The Transformers were hoping that losing weight would make them feel better about themselves and make them more successful. By becoming thinner they discovered a field of mastery.

I have struggled a lot throughout my childhood with low self-confidence. I certainly cannot remember loving myself. I cannot remember having liked myself. There was a great deal about me that I was not satisfied with, including my body, of course (Precursor – Low self-esteem). *And I was very lonely … did a lot of self-harm and the like … I didn't thrive* (Precursor – Loneliness). *But the anorexia itself, it really started with dieting, that I wanted to be thinner. I thought that everything would in fact be better if only I could get thinner. I thought that if I get a little thinner, then maybe I will get more self-confidence, and then things may work out a little bit better. This thing about food was in a way something I could do something about. Because I was not satisfied with myself, then why should others be? I guess I sort of thought that I would love myself more if I was thinner. That it perhaps at least started that way. I think it was that I wanted to change something, and this was something I could do something about, and that I, thought that I would like myself if I became thinner*

(Precursor – Internalized idealization of thinness). *I felt different, and that I wanted to be more like everybody else. I have always been tall, so I felt clumsy and big and stocky and all that. Felt really a bit like the ugly duckling. So it has always been on my mind, that is, that I have been occupied by who is fat and, and that I wanted to be thinner has pre-occupied me since I was a child. As long as I can remember, I have been very pre-occupied by the fact that I was much fatter than everybody else* (Precursor – Heavy body type). *I remember that I threw away my lunch bag in elementary school. I wanted to get thinner back then too, but I did also eat then, I didn't yet have such fixed goals in a way* (Precursor – Worries about food and weight from an early age). *When I seriously started doing something about my weight, was when I was in high school, I think. It wasn't until I managed to get thinner in high school that it got very ... it was then that it, in a way, became ... that I sort of got obsessed about losing weight, in a way. That it then was only going to be more and more and more* (Reinforcer – Feeling high). *And after a fairly short while, I began to get feedback like "Gee, what's happened to you lately?" and "You've lost a lot of weight" and such, and it went pretty fast and I exercised a whole lot and more and more, sort of, so that it would be even better, because that's the way you automatically think. So I actually got a lot of positive attention then, in connection with getting thin and all. And felt that I got to be a little, like, "Wow, finally something that I'm good at"* (Reinforcer – Positive comments on weight loss).

The Punisher

The Punisher pathway typically contained references to precursors such as intense self-hate from an early age (*"I was nine years old when all the hate toward my body and everything to do with myself began"*). This feeling of self-hate could be further triggered by the onset of puberty. Typically, by malnourishing their body the participants appeared to gradually discover how anorectic behaviour could serve as a means to punish themselves and to diminish or extinguish themselves (*"It was a way of killing myself"*). Narratives of The Punisher pathways tended to refer to the emergence of AN as a gradual process. By denying themselves food, The Punisher discovered a form of self-punishment.

I remember being 6 years old when I discovered that I hated my body. This was in pre-school. We stood between two mirrors so that we could see ourselves from both the front and back. And that was the first time I thought, Damn! How ugly I am! Really ugly. And after that, it has constantly bothered me. Constantly (Precursor – Body hatred). *And then the crisis came when*

I had my first period in the fourth or fifth grade. I think I was ten or eleven years old when I had my first period. And then it was –Bang! I didn't want to live any longer. Then every day, I thought that I didn't want to live anymore, and cried and cried and cried. And didn't want to show myself to anyone either (Trigger – Puberty). *I hated myself. The first thing I said to myself in the morning and the last thing I said in to myself in the evening, was that I hated myself. I hate myself. I hate myself. If I could have escaped from my body, then I would have been much better off. But of course, then I wouldn't have had an eating problem. At least, maybe it wouldn't have been visible. Then there wouldn't have been anything for it to be visible on* (Precursor – Body hatred). *I started dieting, up and down and back and forth. In the eighth grade, it really got started. Through not eating, exercising, torturing myself, showering in ice-cold water. Running out in 20 degrees (Celcius) below freezing in a T-shirt. And … yes, indeed, torturing myself through exercising. I exercised a whole lot. Ate very little. Then I felt like I kind of had something to … to take it out on, sort of, through this food thing* (Reinforcer – Punishment). *In the beginning, it was a sort of punishment that I didn't deserve food … but then it got to be that I, it became a sort of rigid pattern that I couldn't break out of. I do not think I can blame judo, but I do not think that it got any better, you know. I learned a whole lot of tricks at judo from those who were much older, because I always travelled with the ones who were much older than me, about how you should diet and how you should do this and that, you know* (Precursor – Role models). *But I see a bit more clearly now, that if I had become better at saying what was going on inside my head, what I was always thinking about, it's not certain that it would have taken hold as hard as it has… As it is now, it sounds completely sick. But that's the way it was. I really wanted to just jump out of my body. That was also why I just wanted to die. I couldn't care less, if I had disappeared from the face of the earth instead, right? And the thing is, if you've ever had that feeling, it will always be there. So that it comes from time to time. Again and again. For I must admit that even though I'm in treatment here, my greatest goal is still to starve myself to death, that's what I long for* (Precursor – Wish to die).

Sense of mastery

Sense of mastery refers to AN as a means to cope with challenges in life. Although the perceived pathways differed in terms of precursors, triggers, reinforcers and level of self-determination, one thing they all had in common was that restrictive eating was described as a means to cope with or master challenges in life. We found that all four pathways in one way

or another contained one or more sequences where restricted eating was regarded as mastery over challenges in life. Based on this finding, we concluded that "sense of mastery" was the central theoretical concept[32] that could be understood as an overall reinforcing factor in the emergence of AN in all pathways. The challenges that the participants tried to master varied significantly, but the way of taking on these challenges through restricted eating was a common theme. These specific challenges included feeling overwhelmed by negative emotions (The Avoidant), straining with the sustainment of high achievement (The Achiever), low self-esteem (The Transformer), and longstanding hatred towards own body (The Punisher). Thus, the four pathways could be described as corresponding to different types of mastery. Because the life circumstances with which they tried to cope through the use of anorectic behaviour were different, but their methods of mastery – restricted eating and thinness – were the same, we regarded the differences between pathways as different projects of anorectic mastery rather than as different types of mastery.

DISCUSSION

This study had the following aim: to identify common structural components in the participants' narratives that could be used to describe possible differences in the participants' stories about how their AN emerged. It is widely accepted that the causes of AN are complex and multifactorial (Striegel-Moore & Bulik, 2007; Polivy & Herman, 2002). By analyzing the common structural components and the different combinations of these components in the narratives we have tried to clarify some overarching pathways in the patient's perspective of the emergence of AN. We suggest that recognizing patients' perceptions of how their illness emerged should be a crucial part of any psychotherapeutic approach to AN. We do not claim, however, that patients' perceptions of their pathway into AN necessarily reflect objective risk factors for the development of AN - even though this might be the case.

We found that AN-patients' narratives about the emergence of AN could be decomposed into the four main structural components of precursors, triggers, reinforcers and awareness of self-determination. By analyzing common features and variations in these four components we could identify one common denominator – sense of mastery – and four different perceived pathways to AN, corresponding to different mastery projects; The Avoidant, The Achiever, The Transformer and The Punisher.

While The Achiever and The Transformer types of perceived pathways are characterized by mastery projects implemented with high awareness of self-determination, The Avoidant and The Punisher types involve low levels of awareness of self-determination. In addition, The Achiever and The Transformer pathways seem to involve recognition of the positive effects of anorectic behaviour at an earlier stage than the Avoidant and the Punisher pathways. The Punisher pathway seems to deviate significantly from the three other types by including precursors of intensive self-hate directed either towards the self as a whole or directed specifically toward the body.

Treatment of AN always carries the risk of becoming a pseudo-treatment because patients are often ambivalent to change (Nordbø *et al.,* 2012; Vitousek, Watson & Wilson, 1998). Because many AN patients are also likely to be other-oriented (Geller, Cockell, Hewitt & Goldner, 2000), they might participate in a therapeutic project that does not target their own experience of how their problems emerged simply as a means to please the therapist and to be "a good patient". Because the mastery projects of the Avoidant and the Punisher perceived pathways seem to be characterized by low awareness of self-determination, they might be more difficult to detect in clinical settings than the two other types, that might be more easily verbalized by the patients themselves. The Achiever and The Transformer perceived pathways might also be more easily recognizable because they converge better with most clinical literature (Bruch, 1978; Hinz, 2006) and how lay people perceive AN and how and why it emerges (Higbed, 2010).

The Avoidant perceived pathway illustrates the emergence of AN as a way of coping with negative emotions and social insecurity. Avoidance of emotion has been linked to the phenomenology of AN from a theoretical (Fox, Federici & Power, 2012), empirical (Brockmeyer, Holtforth, Bents, Kammerer & Herzog, 2012; Corstorphine, Mountford, Tomlinson, Waller & Meyer, 2007; Wildes, Ringham & Marcus, 2010) and patient perspective (Nordbø *et al.,* 2006; Espeset *et al.,* 2012). It has been proposed to be a core element of the pathology of AN, and a study by Wildes and colleagues (2010) found that AN patients seem to have higher scores on emotional avoidance than patients with other mental illnesses. Our study suggests that the use of starving to avoid negative emotions might be established more or less "by accident" and that patients might have low awareness about the effects of this behaviour, as they "slide" into AN.

In The Achiever perceived pathway, the emergence of AN is linked to multi-mastery being substituted by mono-mastery – the mastery of losing weight. The patients' problem of

being overwhelmed with others' and their own demands to be high achievers in everything they do, is solved by focusing on one concrete goal: losing weight. According to clinical reports, patients with AN are often characterized as high-achievers (Bruch, 1978) before the onset of the eating disorder. They also tend to be conscientious, other-oriented, and accommodating of the needs of others before considering satisfying their own needs (Hinz, 2006). According to Hilde Bruch (1978), patients with AN may have an overwhelming feeling of ineffectiveness despite the fact that they are often high-achievers in academics, sports, and art. In the Achiever perceived pathway, as soon as these patients manage to lose weight, the experience of achievement in this area helps them regulate this feeling of ineffectiveness and to experience a more concrete, stable, and achievable focus of mastery in life.

The Transformer perceived pathway is characterized by an internalized idealization of thinness combined with low self-esteem and the determination to change one's personality by losing weight and becoming thin. Characteristic of this type of perceived pathway is the patients' ideals of thinness that have often been internalized from an early age. In the narrative of the Transformer perceived pathway, the patients report a long history of feeling unrecognized and unsuccessful. They think that losing weight will make them become successful and feel better. In previous research on patients' views of AN, increased self-esteem and the use of AN as a means of changing identity have been reported (Nordbø *et al.,* 2006; Williams, 2012). Our study suggests that this style of mastery might be extremely rewarding because the results the patients experience from the weight loss (positive comments from others, feeling high) when the eating disorder begins satisfy their expectations of what thinness can do for them.

The Punisher type of perceived pathway presents AN as a means to punish and gradually extinguish oneself. AN can be understood as self-damaging behaviour, and there is an empirically established association between eating disorders and other self-damaging behaviours (Svirko & Hawton, 2007). In our study, precursors to this mastery project are feelings of deep shame and hatred towards the body that are often established early in life. Such intense feelings of shame have been linked to the phenomenology of eating disorders (Skårderud, 2007) as have intense feelings of self-hate and self-critisism (Williams, 2012; Bruch, 1970). Internal shame might be characterized by inner experiences of the self as flawed, inadequate, and unattractive, and such shame is often associated with intense self-criticism and even self-hatred (Gilbert, 2002). The shame described in The Punisher narratives converges well with this definition of internal shame. It is not clear whether shame is a risk

factor for developing an eating disorder, a consequence of the disorder, a part of the phenomenology, or a combination of these factors (Keith, 2009). However, our research points to how such deep shame might be the core element in patients' experiences of how their eating disorder emerged.

Although within the short format of a scientific paper, we have tried to give a more coherent and complex picture of patients' perspectives of perceived pathways into AN than found in many similar studies (Koruth *et al.,* 2012; Nilsson *et al.,* 2007; Nevonen & Broberg, 2000). This produced a pattern of distinctly different types of perceived pathways into AN, corresponding to different mastery projects. A better understanding among clinicians about these variations and their different psychological dynamics might prevent treatment settings from becoming pseudo-treatments. To broaden clinicians' sensitivity to such differences in psychological dynamics between patients with similar symptoms, we will probably need further clinical illustrations of mastery projects and pathways than we have been able to give here – particularly with regard to the less salient types such as The Avoidant and The Punisher.

Our results contribute to the literature in several ways: First, our results expand on previous studies by providing an empirically based structure within which AN patients' perceptions of how their illness emerged might vary in terms of precursors, triggers, reinforcers, and awareness of self-determination. This might be a useful scheme for both clinical and research assessments.

Second, this study adds to the literature by showing that AN might - according to our analysis of patient narratives - emerge through distinctly different perceived pathways corresponding to different mastery projects. This finding is consistent with a well-known paradox in the literature of AN. Despite the severity and destructiveness of anorectic symptoms, these symptoms may serve important psychological functions for the patients (Nordbø *et al.,* 2008; Serpell *et al.,* 1999; Cockell, Geller & Linden, 2002).

Third, this study suggests that even though patients with AN might present similar symptoms, patients' perspectives on the emergence of their problems indicate that similar symptoms can result from a variety of subjective psychological dynamics. Diagnostic manuals such as DSM-5 (American Psychiatric Association, 2013) and ICD-10 (World Health Organization, 1992) categorize patients on the basis of similarity of symptoms. Clinical reports suggest that despite the similarity of symptoms, treatment of AN could possibly be

better and more effectively planned by analyzing the patients' narratives about their pathways into the eating disorder in more detail (Vanderlinden, 2010).

Assuming that the four types of perceived pathways correspond to four different psychological dynamics, we hypothesize that treatment of The Avoidant, The Achiever, The Transformer and The Punisher might require different treatment strategies. Patients with The Achiever and The Transformer perceived pathway to AN might both profit from treatment modalities that emphasizes changing thought patterns of perfectionism and over-evaluation of weight and shape (e.g. CBT-E) (e.g. Fairburn, 2009). Whereas patients with The Punisher perceived pathway might profit from treatment strategies that emphasizes building of self-compassion and reducing shame (e.g. Gilbert, 2009). For patients with pathways to AN corresponding to the Avoidant perceived pathway, an emotion-focused approach, focusing on recognizing and coping with emotional experience (e.g.Dolhanty & Greenberg, 2009) might be a good choice of treatment base.

In drawing clinical implications from this study one should have in mind that these four perceived pathways are not mutually exclusive. Despite the different combinations of structural components, these narratives do have several themes in common, such as low self-esteem, shame and problems with emotional regulation..To be sure how to implement the findings of this study in treatment strategies, further research is needed regarding the prevalence of these pathways and possible differences in treatment response and course of illness in patients with differing perceived pathways to AN. At the present time, however, the four perceived pathways to AN should be integrated in the treatment provider's conversations with patients about their pathways to AN, to be sure that patients' own perspective of their illness development are sufficiently described, understood and shared in treatment settings. Insofar, further discussion of the clinical implications of our findings lies outside the scope of this paper.

There are several limitations to this study. Even though recognition of patients' perceptions of how their illness emerged might be a crucial part of any psychological treatment approach to AN, patients' perceptions do not necessarily reflect either the actual course of illness or causal or risk factors for the development of the illness. Neither do we know whether the different types of perceived pathways are linked to treatability or to prognosis. In addition, the anorectic mastery projects detected in this study are not fully mutually exclusive. Patients might relate their AN to other combinations of structural components than we were able to detect in this study. Due to our sampling procedures our

sample is not representative of all AN patients. Hence, we cannot exclude that sample bias has influenced the types of perceived pathways that we identified in this study. By using a representative sample we might have found additional narratives, or the pathways described in this study may have been even more clearly articulated. Patients' narratives about how an illness emerged can only be studied retrospectively, i.e. the data have to be collected after the experience to be studied has occurred. Retrospective data will always be subject to possible recall bias and other similar factors that influence the development of opinions. The participants in this study were long-term patients, who all had some treatment experience, and we do not know the degree to which the patients' narratives were influenced by their treatment providers views of the emergence of AN. The patients' narratives about these issues are also likely to have been influenced by the experiences of living with AN over time. If our purpose had been to describe how unexperienced patients in an acute phase of AN understood the emergence of AN, the possible memory bias and influences from treatment providers' views on the narratives would have been a serious limitation. However, because our specific aim was to understand experienced patients' perceptions of how they came to develop AN – including possible memory bias or influences from treatment providers' views – this is a less relevant objection. Importantly, due to our choice of sample, the narratives found in this study might appear different in patients in a more acute phase of AN. Thus, the generalization of the narratives of our study to less experienced patients who are in a more acute phase of AN is not known. Also, we cannot exclude that the different recovery status of the participants in this study (recovered versus actively in the phase of illness) have influenced the patients' descriptions of their perceived pathways to AN. The possible influence on the narratives by treatment providers' views might affect the generalizability of the results to other contexts with different treatment traditions. Because our study was restricted to AN patients, the generalization to other eating disorders is also not known. However, as eating disorders occur on a continuum and often have a heterogeneous course (Fairburn & Bohn, 2005; Fairburn & Harrison, 2003), we cannot rule out that the perceived pathways may be transferable also to other types of eating disorders (American Psychiatric Association, 2013). Our conceptualization of the patients' narratives is based on different qualities of experience among Norwegian women with AN in the Norwegian health care system, and we cannot rule out that additional narratives might have emerged in other contexts.

Conclusion

Establishing a therapeutic alliance with AN patients is considered difficult (Warren *et al.,* 2009; Vitousek *et al.,* 1998), and there is a lack of evidence to recommend the use of one method over another in the treatment of AN (Bulik *et al.,* 2007; Fairburn, 2005). In this regard, recognition and integration of the patient's understanding of her or his problems in the treatment strategy should be given high priority (Nevonen & Broberg, 2000; Geller, Brown, Zaitsoff, Goodrich & Hastings, 2003). According to the results of this study, the common denominator behind the emergence of AN, in experienced patients, is an attempt to master the challenges of life. We found four distinctly different types of perceived pathways into AN: The Avoidant, The Achiever, The Transformer and The Punisher. All of them contain complex combinations and varying degrees and qualities of precursors, triggers, reinforcers, and self-determination. This indicates that a shared set of symptoms – such as in AN – can result from very different psychological dynamics that might need to be met therapeutically in quite different ways and to be taken into consideration when diagnostic tools are being refined.

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