

Causes and Recovery in Anorexia Nervosa: The Patient's Perspective

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Abstract: Objective: We explored anorexic patients' subjective accounts of the causes of their anorexia and of the factors that fostered recovery. Subjective accounts could assist in understanding this complicated and often intractable disorder. **Method:** All female new referrals to an eating disorders service underwent extensive interviews including open-ended questions about their beliefs concerning the causes of their anorexia nervosa and factors that led to recovery. Responses were categorized by two independent raters. **Results:** The most commonly mentioned perceived causes were dysfunctional families, weight loss and dieting, and stressful experiences and perceived pressure. The three most commonly cited factors contributing to recovery were supportive nonfamilial relationships, therapy, and maturation. **Discussion:** Individuals with anorexia nervosa perceive both external (family environment) and personal factors (dieting and stress) as contributory to their disorders. The results underscore the importance of interpersonal factors in recovery from anorexia nervosa and suggest that attention to this area in treatment may be beneficial. © 2003 by Wiley Periodicals, Inc. *Int J Eat Disord* 33: 143–154, 2003.

Key words: anorexia; causes; recovery; family; outcome

INTRODUCTION

Despite a substantial body of research, there is still no consensus among researchers and clinicians on the etiology of anorexia nervosa (AN). The ability to treat the disorder

We dedicate this article to the memory of Alison Pickering whose skill as an interviewer made this project possible and whose humanity, humor, compassion graced our lives.

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effectively and efficiently remains elusive, with the mean duration of treatment being approximately 5 years (Strober, Freeman, & Morrell, 1997). The purpose of this article was to assess the subjective experience of women who had a past or current diagnosis of AN, particularly the factors that caused their AN and contributed to their recovery.

Etiology of AN

Risk factors for the illness fall into the sociocultural, family, and individual domains. Sociocultural theories focus on the widespread pressure on young girls in Western societies to be thin (Garner & Garfinkel, 1980; Garner, Garfinkel, Schwartz, & Thompson, 1980). The cultural pressures may be necessary conditions for the development of eating disorders, but they are clearly not sufficient. Virtually all young women are exposed to these risk factors and yet only a very small percentage develop AN.

Dieting behavior may be the most well-established risk factor for the development of AN (Hsu, 1997; King, 1989; Marchi & Cohen, 1990; Patton, Johnson-Sabine, Wood, Mann, & Wakeling, 1990; Steinhausen, 1994). In their longitudinal study, Patton, Selzer, Coffey, Carlin, and Wolfe (1999) indicated that severity of dieting is the most important predictor of the development of an eating disorder in adolescent girls. Earlier age of dieting is also associated with increased risk (Casper & Jabine, 1986). Although dieting is an important behavioral precursor, only a small percentage of women who diet develop a clinically diagnosable eating disorder (Attie & Brooks-Gunn, 1989; Patton et al., 1990).

The family has also been implicated in the pathogenesis of AN. A family history of AN (Strober, Lampert, Morrell, Burroughs, & Jacobs, 1990) or other weight issues (Halmi, Struss, & Goldberg, 1978; Steiger, Stotland, Trottier, & Ghadirian, 1996) and other psychiatric disorders such as depression and anxiety disorders (Lilenfeld et al., 1998; Råstam & Gillberg, 1991) are more common in the family members of women with AN than in the family members of controls. Specific patterns of family interaction have been observed such as rigidity, overprotectiveness, excessive control, and marital discord. However, there is no evidence of a "typical" anorexia family (Palmer, 1990; Pope & Hudson, 1989).

Individual temperament and personality features (Bulik, Sullivan, & Joyce, 1999; Klump et al., 2000) such as harm avoidance (Bulik, Sullivan, Fear, & Pickering, 2000; Bulik, Sullivan, Weltzin, & Kaye, 1995), obsessionality (Pollice, Kaye, Greeno, & Weltzin, 1997; Speranza, Corcos, Levi, & Jeammet, 1999), perfectionism (Davis, 1997; Halmi et al., 2000; Szabo & Terre Blanche, 1997), and low self-esteem (Button, Sonuga-Barke, Davies, & Thompson, 1996; Silvera et al., 1998) are also premorbid traits that increase the risk of developing AN.

Several authors have shown that psychological stress or stressful life events can trigger the onset of AN. However, the nature and identity of these stressors remain poorly defined (Beumont, Abraham, Argall, George, & Glaun, 1978; Casper & Jabine, 1986; Pyle, Mitchell, & Eckert, 1981; Strober, 1984).

There is a substantial genetic component to the etiology of AN (Bulik et al., 2000; Fairburn, Cowen, & Harrison, 1999; Gorwood, Bouvard, Mouren-Simeoni, Kipman, & Ades, 1998; Kaye et al., 2000; Kipman, Gorwood, Mouren-Simeoni, & Ades, 1999; Klump, Miller, Keel, McGue, & Iacono, 2001; Wade, Bulik, Neale, & Kendler, 2000). Therefore, we need to understand how environmental factors interact with genetic predisposition to lead to the emergence of AN.

Outcome of AN

Women with AN often respond poorly to treatment (Kaye, Strober, Stein, & Gendall, 1999; Löwe et al., 2001; Strober et al., 1997) and our knowledge of prognostic factors is incomplete (Garfinkel & Dorian, 1997). Outcome studies have shown that AN is associated with substantial mortality and chronicity (Herzog, Deter, Fiehn, & Petzold, 1997; Sullivan, 1995). Patients with a past history of AN, even if recovered, retain characteristics such as perfectionism, cognitive restraint, and a preoccupation with symmetry and exactness (Bulik et al., 2000; Srinivasagam et al., 1995) and continue to maintain a body mass index (BMI) that is below that of the control population (Bulik et al., 2000; Strober, 1980; Sullivan, Bulik, Fear, & Pickering, 1998).

Predictors of good or poor outcome have been inconsistently identified. Predictors of outcome include body weight and menstrual function (Baran, Weltzin, & Kaye, 1995; Hsu, Crisp, & Harding, 1979; Strober et al., 1997); age of onset and duration of illness (Hoffman & Halmi, 1993); intrafamilial disturbances (North, Gowers, & Byram, 1997; Strober & Humphrey, 1987; Strober et al., 1997); comorbid psychiatric disorders (Halmi et al., 1991; Kennedy, McVey, & Katz, 1990), psychological and social functioning (North & Gowers, 1999); laboratory findings (Herzog et al., 1997); and duration and number of hospitalizations (Hoffman & Halmi, 1993; Steinhausen, Rauss-Mason, & Seidel, 1991).

Little attention has been paid to the personal perspective of patients on the causes of their eating disorder as well as the factors that contribute to recovery. To our knowledge, only three studies (Beresin, Gordon, & Herzog, 1989; Hsu, Crisp, & Callender, 1992; Rorty, Yager, & Rossotto, 1993) have considered patients' opinions about their eating disorders. These studies consist of small samples. Beresin et al. (1989) interviewed 13 recovered women with AN. They assessed the perceived causes of the disorder and the therapy and nontherapy-related factors that contributed to recovery. All of the subjects perceived family conflict as particularly deleterious. Participants described their mothers as intrusive, unable to tolerate the child's growth and development, and excessively concerned with appearances. Fathers were described as distant, overinvolved with work, and often prone to alcohol abuse. A number of women attributed the onset of AN to troubling romantic experiences. Therapy was viewed as helpful in dealing with emotions. Medications were not perceived as being able to alleviate AN symptoms but were viewed as helpful in relieving mood and anxiety symptoms. Life experiences such as separation from family, work, or school and meaningful relationships were considered as important as therapy in the recovery process. Six recovered anorexic patients (Hsu et al., 1992) described psychotherapy, willpower, getting married and having children, and increased self-confidence as recovery factors. In these studies, participants highlighted the importance of being understood as central to their recovery.

In the current study, we further explore subjective appraisals of causal and recovery factors in 69 women with a lifetime history of AN.

METHODS

Our data are from a case-control study conducted by Sullivan et al. (1998). Using clear diagnostic definitions and structured methodology, we identified, located, and interviewed 70 women who were referred for treatment of AN an average of 12 years earlier (a mean of 15.4 years after onset of AN) to describe their intermediate to long-term outcome. Using a case-control design, we compared the outcome of cases with AN to the status of a random community control group screened for the presence of AN. The study

was reviewed and approved by the local ethical committee and all subjects provided written informed consent.

In this study, we restrict our analysis to the women with AN to assess their perceptions of factors that contributed to the development of and recovery from their eating disorder. Only one woman completed an abbreviated assessment and was excluded from this analysis.

Case Definition and Ascertainment

Potential cases were drawn from the records of the Eating Disorders Service at The Princess Margaret Hospital in Christchurch, New Zealand. Women assessed or treated by the Eating Disorders Service for the first time from January 1, 1981 to December 31, 1984 were eligible for inclusion in this study. The hospital record of every new referral seen during 1981–1984 was independently reviewed and abstracted (using a standardized form) by two trained medical students under the close supervision of P.F.S. Following a consensus conference between the two raters and P.F.S., potential cases were defined as anyone first seen by the Eating Disorders Service from 1981 to 1984 who met criteria for definite or probable AN as outlined in the 3rd edition (DSM-III; American Psychiatric Association [APA], 1980) and the 3rd Rev. edition (DSM-III-R; APA, 1987) of the Diagnostic and Statistical Manual of Mental Disorders.

Data Collection Protocol

After cases and controls were contacted and agreed to participate, an interview was scheduled with women who met lifetime DSM-III-R criteria for AN. The interview had several components. The first component was a standardized and structured diagnostic interview, the Diagnostic Interview for Genetic Studies (DIGS; Frances, 1994; Nurnberger et al., 1994). A specific section of the interview was dedicated to questions regarding patients' personal opinion about the causes of their AN as well as the factors that contributed to their recovery. The interviewers recorded verbatim the responses of the subjects. Each interview was reviewed by two of the authors (F.T. and C.M.B.) to develop categories of causes. The most common categories are listed in Table 1. We included an "other" category to capture unusual experiences that individuals' believed were instrumental in causing their disorder. F.T. and C.M.B. reviewed the interviews again and coded individual responses as present or absent for each category. It was allowable to have positive scores in more than one category. The same procedure was followed for the recovery variables (Table 2).

Recovery was defined as the absence of a diagnosis of any eating disorder (AN, bulimia nervosa [BN], eating disorder not otherwise specified [EDNOS]) on the basis of DSM-III-R criteria at the time of interview. All participants had been treated at the eating disorders program at the Princess Margaret Hospital, which included weight stabilization, individual and group supportive psychotherapy, family counseling, medication if necessary, and nutritional rehabilitation.

Statistical Analysis

Data were analyzed by the JMP program (SAS Institute, 1994). We used Cohen's kappa (Cohen, 1960) to determine interrater reliability for both causal and recovery factors. We also used simple statistics to describe sample features and to rank the percentages of subjects identifying the different factors as their reasons for the development of and recovery from AN.

Table 1. Examples of causes

	Causes
Self-esteem	"No self confidence"; "low self-esteem, lack of confidence"
Perfectionism	"Perfectionist"; "wanted to be seen to be perfect"; "perfectionist—didn't look the way I wanted to"
Achievement	"Extreme goals and ideals"; "high achiever"; "wanting to achieve something, be excellent at something"; "has always set very high standards"
Parental expectation	"Parents never satisfied"; "parents strict, high expectation"; "high expectation from father—pressure to achieve at school and university"
Family dysfunction	"Family always very controlling"; "a lot of fights and problems"; "issues with mother"; "mother dominant, overpowering, negative"; "parents constantly bickering"; "parents' messy divorce"
Family weight and food issues	"Lived with obese aunt, always dieting; mother fat. . ."; "food always a big issue in the family, used as reward"; "family stress on slim, healthy eating, exercise"
Weight loss/dieting	"Diet got out of control"; "a bit overweight, started dieting, got out of hand"
Sexual abuse	"Raped by older boyfriend"; "sexual abuse by an uncle"
Inappropriate comments	"Everyone teasing"; "comments at school"; "teacher at school constant put-down"
Mood	"Depression"; "low mood"; "unhappy kid"
Adolescence	"Puberty" "adolescence—unprepared for changes"; "hated puberty"; "not accepting maturing body, wanting to be child-like in appearance"
Control	"Eating was one thing that could be controlled"; "felt it gave me some control over my life"
Pressure/stress/frustration	"Stress, part of a bad time in life"; "pressures: exams, boyfriend pressured to get married, father very ill"; "stressful time"; "stress at work—losing job—pressure at home"
Loss	"Grief at boyfriend's death"; "father's sudden death"

RESULTS

The sample comprised 69 women with a lifetime history of AN. The mean age at the time of the interview was 32.3 years ($SD = 7.8$). Of the total sample, 42.0% of women were diagnosed with the restrictor subtype of AN and 58.0% had lifetime BN or subthreshold lifetime BN. In addition, 46.4% were married, the average global assessment of functioning score (GAF) was 68.8 ($SD = 16.0$), and the average BMI was 20.1 ($SD = 2.1$). At the time of interview, 10.1% of patients were not recovered. The average age at onset was 16.9 years ($SD = 4.1$) and the average age at presentation for treatment was 20.9 years ($SD = 8.0$). The interval between the onset of AN and the interview was 15.4 years ($SD = 7.0$).

Rater Agreement

The agreement between raters was acceptably high for both causes and recovery variables. Excluding the other category, the mean kappa for causes was 0.87 (range, 0.64–1.00) and for recovery 0.87 (range, 0.52–1.00). When agreement was not perfect between the two raters, a consensus rating was established which was entered into the final analysis.

Table 2. Examples of recovery factors

	Recovery
Maturation	"Time, maturity..."; "growing up"; "older, more mature"
Supportive relationship	"Met husband"; "good, healthy relationship with husband, unconditional love and acceptance"; "supportive husband—treated her normally all the way through it"; "being valued by husband"
Supportive friendship	"Good, really close friends"; "two excellent friends who treated me the same all the time, no matter what"
Support from other patients	"Knowing other patients, support/discussion"
Therapy	"Therapy, group sessions"; "good therapy: people listening, understanding"; "Gestalt therapy"
Medications	"Medications to deal with mood problems"; "medications probably lowered anxiety"
Leaving home	"Leaving home: distance from parents"; "left home, reduction in pressure"
Religion	"Prayer, faith in God"; "Christianity"
Children/pregnancy	"Kids growing up, wanted to be there for them"; "wanting to be OK for the kids"; "pregnancy—totally refocused life"
"Waking up"	"Realized seriousness of situation and snapped out of it"; "realized I had to stop"; "just know it was time to get better"
Increased self-esteem	"Feeling better about self"
Willpower	"Determination to get out of it"; "strength of character, determination to get it out of my life"; "strong personality"
"Good loss"	"Leaving husband"; "splitting up"
Job	"Getting job"; "work place—being valued in jobs"; "broad range of experiences through number of different jobs"

Perceived Causes of AN

More than one-third of patients highlighted family dysfunction as a contributing factor to the development of their eating disorder. This category included family features such as poor parental care/childhood deprivation, parental overcontrol, poor relationship with parents, pervasive family tension/fights, and emotional abuse. The next most commonly perceived causes were weight loss/dieting and stress and frustration (Table 3).

Perceived Factors Related to Recovery

Table 4 presents the categories perceived to be associated with recovery and the percentage of individuals who cited them as important to their own recovery. The three most commonly mentioned factors were a supportive relationship or partner, maturation or growing out of the disorder, and therapy or counseling.

Recovered Versus not Recovered

A comparison of causes reported by individuals who had/had not recovered showed that individuals who had not recovered at the time of the interview were more likely to have cited family weight and food issues ($\chi^2 = 4.7, p = .03$) and low self-esteem ($\chi^2 = 6.2, p = .01$) as causal factors.

Table 3. Percentage of individuals citing each causal category

Causes	Percentage (<i>n</i> = 69)
Family dysfunction	34.78
Weight loss/dieting	21.74
Pressure/stress/frustration	20.29
Inappropriate comments	15.94
Control	14.49
Family weight and food issues	13.04
Sexual abuse	13.04
Mood	11.59
Low self-esteem	11.59
Loss (grief)	10.15
Adolescence	10.15
Perfectionism	10.15
Achievement	10.15
Parental expectation	7.25
Other	15.94

BN Versus Restrictor AN

Individuals with the bulimic subtype of AN more frequently cited high parental expectations as causal ($\chi^2 = 3.9, p = .05$). Due to small group size, we were unable to perform subgroup analyses on recovery variables.

DISCUSSION

To our knowledge, this is one of the few efforts to assess the subjective perception of causal and recovery factors in AN.

Causal Factors

Family Dysfunction

The causal factor most frequently mentioned by patients was a dysfunctional family. This finding is broadly consistent with existing literature (Lilenfeld et al., 1998; Logue,

Table 4. Percentage of individuals citing each recovery factor

Recovery	Percentage (<i>n</i> = 51)
Supportive relationship (partner)	27.45
Maturation	23.53
Therapy/counseling	21.57
Children/pregnancy	17.65
Waking up	15.69
Leaving home	15.69
Supportive friendship	13.73
Increased self-esteem	13.73
Will power	11.77
Family support	9.80
Job	7.84
Medicines	5.88
Religion	3.92
"Good loss"	3.92
Support from other patients	1.96
Other	11.77

Crowe, & Bean, 1989; Steiger, Liquornik, Chapman, & Hussain, 1991; Strober et al., 1987, 1990). Although several studies have documented differences in family interaction patterns between anorexic families and controls (Steiger et al., 1991; Waller, Slade, & Calam, 1990), there does not appear to be a unique family interaction pattern that is characteristic of AN patients (Garfinkel & Garner, 1982). Overprotectiveness has been implicated in the etiology of the disorder (Calam, Waller, Slade, & Newton, 1990; Palmer, Oppenheimer, & Marshall, 1988) and may antedate the onset of the illness (Shoebidge & Gowers, 2000). Regardless of the nature of the dysfunction, many patients with AN attribute the etiology of their disorder to factors associated with dysfunction in the family.

Dieting/Weight Loss

For more than 20% of the patients, a diet or the intention to lose weight preceded the onset of the disorder. Most of them described a loss of control of the dieting behavior. This finding is also consistent with previous studies (Hsu, 1997; King, 1989; Marchi & Cohen, 1990; Patton et al., 1990; Steinhausen, 1994), confirming that dieting is a frequent antecedent of AN.

Stress

It is particularly noteworthy that about 20% of patients cited some form of stress as causal in their eating disorder. Studies of temperament and personality of women with AN suggest that they are often harm avoidant (Bulik et al., 1995; Klump et al., 2000; Strober, 1980). In addition, AN individuals commonly report histories of childhood anxiety disorder (Braun, Sunday, & Halmi, 1994; Bulik, Sullivan, Fear, & Joyce, 1997; Bulik, Sullivan, Fear, & Pickering, 1997; Deep, Nagy, Weltzin, Rao, & Kaye, 1995; Pollice et al., 1997). Such temperaments or anxiety proneness may render these individuals particularly vulnerable to stressful life events. Their temperaments may interact adversely with stressful experiences to create a window of opportunity for the emergence of AN. Individuals genetically predisposed to AN may find that starvation produces an anxiolytic effect. If so, starvation may decrease the subjective negative experience associated with these "trigger" adverse life events.

Subgroup Analysis

Previous studies have shown that families of individuals with bulimic behavior are more conflictual and less cohesive (Fornari et al., 1999; Johnson & Flach, 1985; Schmidt, Slone, Tiller, & Treasure, 1993; Strober, Salkin, Burroughs, & Morrell, 1982). We also found greater reports of family dysfunction (as well as child sexual abuse) among our subjects with AN of the bulimic subtype.

Patients with a poor outcome more frequently reported a history of childhood sexual abuse, a family with weight and food concerns, and lower self-esteem. The current design cannot address whether these factors contribute to poor outcome.

Recovery Factors

Relationships and Maturation

Because there is no universally effective treatment for AN, it is useful to investigate which therapeutic and life experiences play the most important roles in the outcome from the perspective of the patients. In our sample, relationships (either with a partner or a therapist) played a major role in recovery. Patients said that a supportive relationship

was the driving force that assisted them in recovery. Many patients said they matured out of the disorder. In many cases, becoming pregnant or desiring to start a family fueled that process. This finding is consistent with the literature that describes an improvement in symptomatology during pregnancy (Blais et al., 2000).

Treatment

Interestingly, very few individuals reported that pharmacologic treatment played a significant role in recovery. In our sample, only 4 patients mentioned medication as a recovery factor. None of these individuals claimed that medication affected core AN symptoms, but rather noted improvements of comorbid mood and anxiety symptomatology.

These subjective reports parallel the literature in which there is no strong evidence for a specific and effective pharmacologic treatment for AN.

Strengths and Limitations

The strength and, at the same time, the limitation of this study is the focus on the patients' subjective perspectives. Individuals often try to give meaning to experiences in their life and may grasp onto stressful experiences for their explanatory power in creating a plausible story for why they developed an eating disorder ("effort after meaning," Cohen & Cohen, 1984). The perspective of the patients, together with clinical data, can provide a novel and rich understanding of etiology and outcome factors in AN.

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