Outcome and prognostic factors for adolescent female in-patients with anorexia nervosa:

9- to I4-year follow-up

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Background Earlier studies have indicated poor long-term outcomes for patients with anorexia nervosa.

Aims To study health and social outcomes of adolescent in-patients with anorexia nervosa in relation to prognostic factors.

Method A register study based on socio-economic and health data was conducted for a national cohort of female residents in Sweden born between 1968 and 1977, including 748 in-patients with anorexia nervosa.

Results At follow-up 9–14 years after hospital admission, 8.7% of patients with anorexia nervosa had persistent psychiatric health problems demanding hospital care and 21.4% were dependent on society for their main income; the stratified relative risks were 5.8 (95% CI 4.7-7.6) and 2.6 (2.3-3.0) respectively, compared with the general female population. The mortality rate for patients with anorexia nervosa was 1.2% and the stratified risk ratio for maternity was 0.6 (95% CI 0.5–0.7). Long duration of hospital care and psychiatric comorbidity were predictors of persistent psychiatric problems and financial dependency on society.

Conclusions The outcome in this cohort of adolescent in-patients with anorexia nervosa was considerably better than that reported in previous studies.

Declaration of interest None.

Most follow-up studies of patients with anorexia nervosa have indicated that poor long-term outcome is common. A recent meta-analysis suggests a mortality rate of 5% (Steinhausen, 2002) and long-term impairment has been reported in as many as 50% of patients with this disorder (Steinhausen et al, 1991; Deter & Herzog, 1994; Herzog et al, 1996; Finfgeld, 2002; Fisher, 2003). Age at onset, duration of in-patient care, comorbidity and social problems have been identified as important prognostic factors (Lowe et al, 2001; Finfgeld, 2002; Steinhausen, 2002). Because of the unclear inclusion criteria with regard to age and severity of disease, and the comparatively small sample sizes, there is still considerable uncertainty about the longterm outcome of anorexia nervosa. In this study we used the Swedish national registers to study outcome and prognostic factors of female in-patients treated for this condition in a national cohort of Swedish adolescents.

METHOD

Study population

The study was based on data from national registers in Sweden containing information about socio-economic and health indicators of the entire Swedish population. In these registers residents can be tracked from birth to death by a unique personal identification number. The study population consisted of all female residents born between 1968 and 1977 who were recorded in the Register of the Total Population on 31 December 1986: this totalled 529 369 individuals. Anorexia nervosa was defined as a main or comorbid diagnosis of anorexia nervosa at discharge from a hospital, according to ICD-9 criteria (World Health Organization, 1978). In all, 748 in-patients with anorexia nervosa were identified in the Swedish Hospital Discharge Register with an admission date during the period

1987–1992. The comparison group consisted of all other females in the study population born in 1968–1977.

Socio-demographic variables

The mothers of the study group were identified in the Swedish Multi-generation Register. The year of birth of the mothers and those studied and the geographical location of their place of residency were identified in the Register of the Total Population in 1986. Maternal age refers to the age of the mother at the time of the birth of the child. Socio-economic status, housing and single parenthood for the head of the household were identified from the Swedish Population and Housing Census of 1985. Socio-economic groups were identified according to a classification created by Statistics Sweden, based on the occupation of the head of the household (Statistics Sweden, 1982). This five-category classification was dichotomised into low (manual workers and grade I white-collar workers) and high (white-collar workers grades II and III).

Comorbidity and duration of hospital care

The total number of days in hospital care with a diagnosis of anorexia nervosa during 1987–1983 (i.e. 1 year after the last possible admission date) was calculated based on information from the Swedish Hospital Discharge Register for the patient study group. Comorbidity was identified in the same register during the same years with a main or contributory diagnosis of depression, personality disorder, alcohol abuse, drug dependency and/or any other diagnosis in the psychiatric chapter of ICD–9. Suicide attempts were identified by an external cause diagnosis of E950–E959 or E980–E989 (ICD–9).

Outcome variables

Two sets of outcome variables were used. Health outcome variables were assessed with information from the National Cause of Death Register for 1987–2001 (death) and the Swedish Hospital Discharge Register for 2000–2002 (hospital care for a psychiatric disorder, substance misuse, suicide attempt and/or anorexia nervosa according to ICD–10; World Health Organization, 1992). A summarised 'poor health' outcome indicated death and/or a hospital discharge for any of the mentioned diagnoses

during 2000–2002. Births were identified in the Medical Birth Registry for the period 1987–2001.

Social outcome variables were created for residents in Sweden in 2001 (735 individuals in the anorexia study group and 477 548 in the comparison group) using information about that year from the Total Enumeration Income Survey:

- (a) disability pension, indicating lifelong pension because of illness;
- (b) illness benefits, indicating temporary economic support because of illness from the national health insurance;
- (c) employment, indicating having an income from employment in November 2001;
- (d) student, indicated by having received educational benefits;
- (e) living with biological parents;
- (f) single parenthood.

The number of months in which each individual had received social assistance during 2001 was identified from the Swedish Social Assistance Register and the highest completed educational level as of December 2001 was derived from the Swedish Educational Register. Education was categorised as 'basic' if the person had completed no more than the compulsory 9 years of schooling, and as 'postsecondary' if at least one educational level had been completed after secondary school. A summarised 'financial dependency' outcome variable was created which indicated at least one of the outcomes of disability pension, 6 months or more of social assistance and/or a main income from illness benefits during 2001.

Statistical analysis

Chi-squared analyses were used to test bivariate associations. Multivariate risk ratios for the summarised variables as described above were calculated using the Mantel-Haenszel method for pooling over strata (Rothman & Greenland, 1998). We calculated 95% confidence intervals using the test-based method. Interaction effects were tested in logistic regression models and statistical analyses were carried out using the SAS 8.0 software package for Windows.

RESULTS

The socio-demographic characteristics of the 748 in-patients with anorexia nervosa

Table I Socio-demographic indicators of the study population

	Anorexia nervosa	General population		
	(n= 748)	(n=528 621)		
Maternal country of birth, %				
Sweden	88.6	86.6		
Finland	3.5	5.2		
Western Europe	2.8	2.3		
Eastern/southern Europe	3.1	2.4		
Non-European	0.3*	1.7		
Unknown	0.1	0.0		
Missing	1.6	1.7		
Housing, %				
Rented apartment	30.2	33.8		
Own apartment	11.8	11.8		
House	56.0*	52. I		
Residency, %				
Big city	24.3	28.3		
Other urban	52.0	51.1		
Rural	23.7	20.6		
Socio-economic status, %				
Missing or undefined	19.1	20.2		
Low or moderate	40.6	50.1		
High	39.3***	29.6		
Single parent household, %				
Missing data	1.5	2.3		
Yes	11.1	11.6		
No	87.4	86.I		
Child welfare interventions, 1 %				
Yes	4.4***	2.3		
No	95.6	97.7		

I. Child welfare interventions include foster care, institutional placement or support family.

and the general population are presented in Table 1.

In the period 1987-2001, six people in the anorexia in-patient study group (0.8%) died from a cause assumed to be related to anorexia nervosa. Death certificates recorded anorexia nervosa as the underlying cause of death in two cases, suicide in two, degenerative heart failure in one and drug overdose in one. Three more patients died during the follow-up period (two car accidents in which the patient was a passenger and one case of cancer of the uterus), yielding a total mortality rate of 1.2% compared with 0.4% in the general population. When the National Cause of Death Register was checked for deaths with an underlying or comorbid diagnosis of anorexia nervosa during 1987-2001 in the comparison group, two individuals apart from those in the in-patient study group were identified, both having their first hospital admission after adolescence according to the Swedish Hospital Discharge Register.

Table 2 presents crude rates of health outcomes during 2000–2002 and indicators of social adjustment in 2001. During the former period, 8.7% of the patients with anorexia nervosa had been discharged from a hospital with a psychiatric diagnosis compared with 1.3% of the general population. Table 3 presents multivariate analyses of health and social outcomes. The stratified relative risk in the anorexia study group was 5.8 for a poor health outcome (death and/or hospital discharge) and 2.6 for being financially dependent on the society compared with the general population.

Prognostic factors

Table 4 presents frequencies and relative risks of prognostic factors for poor health and financial dependency in the anorexia

 Table 2
 Outcomes of health and social adjustment in patients with anorexia nervosa admitted to hospital in

 1987–1992 in comparison with the general population

	Anorexia nervosa %	General population %
Health outcome variables	n= 748	n=528 62 I
Death in 1987–200 I	1.2***	0.4
Hospital care during 2000–2002 because of		
Anorexia nervosa	4.5***	0.9
Suicide attempt	2.9***	0.4
Other psychiatric diagnosis	4.5***	0.9
Alcohol misuse	0.9***	0.2
Illicit drug misuse	0.9**	0.2
Any hospital admission	8.7***	1.3
Poor health outcome (death or hospital admission)	9.9***	1.7
Social outcome variables	n=735	n=477 548
Soical adjustment in 200 I		
Social benefits > 6 months	1.9	1.2
Illness benefits as major income	7.1	5.5
Disability pension	12.3***	1.9
Financial dependency (any of the above)	21.8***	8.6
Employed	57.7***	73.3
Studies	13.0***	9.2
Lives with parents	9.0*	6.8
Completed education		
Basic (9 years)	11.0**	7.8
Post-secondary	47.7***	40.8

^{*}P < 0.05, **P < 0.01, ***P < 0.001.

Table 3 Frequencies and risk ratios for summarised outcomes and maternity in in-patients with anorexia nervosa in comparison with the general population

		General population	Risk ratio (95% CI)	
	%	%	Bivariate	Stratified ¹
Poor health	8.7	1.3	5.7 (4.5–7.1)	5.8 (4.7–7.3)
Financial dependency	21.4	8.6	2.5 (2.1-2.9)	2.6 (2.3-3.0)
Has given birth	24.7	43.8	0.6 (0.5–0.6)	0.6 (0.5–0.7)

^{1.} Stratified for year of birth, socio-economic status, residency and maternal country of birth.

group. Patients with a long duration of care (>180 days) more often had a poor health outcome as well as a financial dependency outcome (RR=4.6 and RR=2.5 respectively) whereas those with short durations of care (0-28 days) fared better (RR=0.4 and RR=0.5 respectively). Psychiatric comorbidity was associated with a greater risk of poor health (RR=3.6) and financial dependency (RR=3.0).

The socio-economic status and ethnicity of the household of the biological

parents in 1990 had no significant impact on the outcome of the patients with anorexia, but being adopted, growing up in a one-parent household, having a young mother and/or having received child welfare interventions was related to a greater risk of a poor health outcome as well as financial dependency. When the effect of these factors in the in-patient group was compared with the effect in the general population in interaction analyses in a logistic regression model, they were,

however, found to be similar (interaction effects of 1.0-1.2), suggesting that these are general rather than disorder-specific effects.

DISCUSSION

This study suggests that the outcome of adolescent female in-patients with anorexia nervosa in Sweden is better than has been previously reported. However, anorexia nervosa is still a disease with severe negative long-term consequences of various kinds for many patients. The death rate was slightly elevated, the maternity rate was only 60% of the rate in the general population, there was considerable longterm psychiatric morbidity and 21.4% were dependent on society for their main income. An adolescent (at inclusion) study population with this condition usually has a lower mortality rate than patient populations with wider age ranges (Steinhausen, 2002). The mortality rate of 1.2% (0.8% in anorexia-related causes of death) in this study is, however, exceptionally low in comparison with previous research. A recent Swedish register study, for instance, reported a 9- to 14-year mortality rate of 4.5% in adolescent patients with anorexia nervosa in hospital care during 1977-1981 (Lindblad et al, 2006a) and a Danish register study (Emborg, 1999) demonstrated a crude mortality rate of 8.4% at mean follow-up of 10.3 years in a population of adolescent and adult patients with an eating disorder. Somatic conditions caused by prolonged starvation may underlie the low maternity rate in women with the most severe and chronic forms of anorexia nervosa (Fichter et al, 2003). Problems with social life and sexual relationships associated with the eating disorder and comorbid psychiatric disturbances probably contribute more significantly to explaining this phenomenon in the vast majority of patients in a less severe somatic state (Fornari & Dancyger, 2003).

The main prognostic factors in this study were those associated with the severity and psychiatric characteristics of the disorder. The longer the duration of the initial hospital care, the worse was the long-term outcome. One possible interpretation of this association is that the duration of hospital care is an indicator of the severity of the disorder, but it is also possible that hospital care in itself may have harmful effects, as suggested by Gowers *et al* (2000). When

Table 4 Frequencies and risk ratios of prognostic factors for poor health and financial dependency in in-patients with anorexia nervosa in 1987–1992

Prognostic factors	%	(n)	Poor health (n=748)		Financial dependency (n=735)	
			Bivariate RR (95% CI)	Stratified ¹ RR (95% CI)	Bivariate RR (95% CI)	Stratified ¹ RR (95% CI)
Comorbidity						
Personality disorder	3.3	(25)	6.1 (3.1–9.8)		3.3 (2.3-4.7)	
Alcohol misuse	1.1	(8)	0.8 (0.1-4.8)		1.9 (0.8-4.6)	
Illicit drug use	0.5	(4)	5.4 (2.0-14.7)		2.5 (0.9-6.7)	
Depression	2.5	(19)	2.2 (0.2–1.0)		2.9 (1.8-4.5)	
Suicide attempt	7.1	(53)	5.3 (3.4–8.1)		3.3 (2.5-4.4)	
Any psychiatric	16.0	(120)	3.6 (2.3–5.6)	2.1 (1.2–3.6)	3.0 (2.3–3.9)	2.0 (1.4–2.7)
Duration of hospital care						
0–28 days	39.8	(298)	0.4 (0.2-0.7)	0.8 (0.4-1.6)	0.5 (0.3-0.7)	0.7 (0.5–1.1)
> 180 days	18.3	(137)	4.6 (3.0–7.0)	3.1 (1.8–5.4)	2.5 (1.9–3.3)	1.7 (1.2–2.4)
High socio-economic status	39.3	(294)	0.7 (0. 4 –1.1)		0.7 (0.5-1.0)	
Upbringing in one-parent	11.1	(83)	1.7 (0.9–1.1)		1.5 (1.1–1.9)	1.5 (1.0-2.3)
household						
Swedish-born mother	88.6	(663)	0.6 (0. 4 –1.1)		1.0 (0.6–1.5)	
Maternal age at birth						
Young (14–19)	4.8	(36)	1.8 (0.8–3.9)		1.8 (1.2–2.8)	1.6 (1.0-2.2)
Old (35+)	6.4	(48)	0.6 (0.2–2.0)		1.5 (0.9–2.4)	
Rural residency	23.8	(178)	1.3 (0.8–2.2)		1.1 (0.8–1.5)	
Perinatal risk	3.3	(25)	0.4 (0.1–2.7)		0.9 (0.4–2.0)	
Adopted/in foster care	5.9	(44)	2.9 (1.7-5.2)	1.8 (0.9-3.6)	1.9 (1.2-2.9)	1.0 (0.6-1.7)

RR, risk ratio

anorexia nervosa was complicated by psychiatric comorbidity the outcome was also less favourable. Comorbidity in this disorder is a well-described phenomenon with regards to depression and personality disorders, especially of the cluster C type (Rosenvinge *et al*, 2000), and has also been suggested as a negative prognostic indicator in previous studies (Saccomani *et al*, 1998).

More than 20% of the adolescent patients in this study were dependent on society for their main income in 2001. Financial support from society can be an important component of successful therapy during a recovery phase of the disorder, but can also contribute to social disability if taken as an excuse to refrain from social rehabilitation and employment. More knowledge is needed about the effects and best use of these powerful economic tools in modern welfare societies with regard to young people with anorexia nervosa.

We suggest two major explanations of the comparably good outcome in this cohort. First, care of anorexia nervosa has been given priority in Sweden during the 1990s and out-patient psychiatric units

specialising in this disorder have been established in many regions. Second, the medical treatment of nutritional emergency states has improved over time. As a complementary explanation, one may speculate about more or less specific sociocultural factors in Sweden, allowing for a better prognosis than in other countries. Such sociocultural influences on prognosis may be far more complex than the Western values regarding slimness that are commonly cited (Rieger et al, 2001). Comparisons of the mortality of patients with anorexia nervosa in Sweden show a distinct decrease over time (Lindblad et al, 2006a). Such relatively rapid changes are probably better explained by the improved treatment conditions than by socio-cultural changes. Consequently we believe that the improved prognosis may also be valid for other Western countries with similar developments in anorexia nervosa care.

Data collection from national registers carries both advantages and disadvantages. The main advantage of a register design for a follow-up study of anorexia nervosa is that it makes it possible to study an entire population of patients with a standardised inclusion criterion (in-patient care) without attrition. One obvious disadvantage is that the information about the disorder is superficial and does not allow for follow-up of specific symptoms or disabilities. Thus, the persistence of specific symptoms of disordered eating behaviour or the commonly occurring development of other eating disorders treated in out-patient care (Milos *et al.*, 2005) could not be studied.

The selection of patients in a follow-up study is a crucial step with obvious implications for the outcomes. In Sweden the vast majority of patients with anorexia nervosa are given out-patient care. Admission to hospital indicates a severe illness, usually with serious physical complications demanding intensive nutritional therapy. Thus, we believe that our study group is a population of comparably severe cases of anorexia nervosa in relation to all adolescent patients with this disorder in Sweden. One may speculate that the inclusion of male patients would have affected the outcome, but as has been reported elsewhere (Lindblad et al, 2006b) the outcomes for

I. Stratified for all variables in the model and for year of birth.

male in-patients in these cohorts were even better than for female patients.

This study indicates a comparatively favourable prognosis for female patients receiving in-patient treatment in adolescence. Further studies that compare outcomes over time and include non-hospitalised patients with anorexia nervosa are needed to confirm our results.

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