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ORIGINAL ARTICLE

Death from anorexia nervosa: age span and sex differences

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Abstract

The purpose of this study was to assess characteristics of individuals who died from anorexia nervosa by assessing the frequency with which anorexia nervosa is listed as a causal factor related to the death of individuals in the USA. Data from over 10 million death records (all National Center for Health Statistic registered deaths in the USA for 1986–90) were examined for mention of anorexia nervosa as a primary or contributing cause of death. Only 724 were found, which equals an average of 145 annual deaths, and a rate of 6.73 per 100,000 deaths. The age and sex distribution suggests two fatal forms of anorexia nervosa, an early-onset form comprising 89% women and a later form comprising 24% men. The findings suggest that the mortality risk from current anorexia nervosa may be lower than formerly supposed and that it is not confined to young adults and adolescents.

Introduction

Anorexia nervosa is recognized as a psychological disorder affecting mainly young women (American Psychiatric Association, 1984) and recent reports suggest a long-term increasing incidence of the problem (Lucas, 1991; Lucas *et al.*, 1991; Willi & Grossman, 1983). According to the DSM-IV (1984), the diagnostic criteria for this disorder include: refusal to maintain body weight at a minimally normal weight for age and height, resulting in weight dropping to 85% or less of expected; intense anxiety about gaining weight; a disturbance in perception of body weight and shape; undue influence of body weight or shape on self-evaluation; and denial of the serious consequences of current low body weight. In post-menarcheal females, there is also often amenorrhea.

There appears to be a large psychogenic component in the genesis of this disorder, and personality, family, biological and cultural factors are believed to play causal roles (Hsu, 1990; Schlundt & Johnson, 1990; Vitousek & Manke, 1994). Based on several lines of evidence, some researchers have suggested that the number of individuals with anorexia nervosa is virtually at epidemic levels in Western cultures (Lucas, 1991). In Switzerland, the number of new cases of anorexia nervosa who come for treatment is reported to be in the order of 17 per 100,000 females in the age range 12–25 years (Willi & Grossman, 1983), with similar incidence rates reported in the states of New York (Jones *et al.*, 1980) and Minnesota (Lucas *et al.*, 1991). Recent reports claim that approximately 5 million people in the USA suffer from eating disorders and that approximately half of these involve anorexia nervosa (DeAngelis, 1997).

One of the most important characteristics of anorexia nervosa is its lethality. The life-threatening nature of this disorder has been suggested by several long-term follow-up studies which indicate that as many as 20% of anorexics will die of conditions caused by the disease, including the direct medical effects of starvation, acute cardiac failure, chemical and hormonal imbalances and so forth (Ratnasuriya *et al.*, 1991; Theander, 1992). It has also been claimed that as many as half of these deaths will be directly due to suicides (Agras, 1987), although most estimates tend to be considerably lower than this (Coren & Hewitt, 1998; Patton, 1988; Theander, 1992). In a recent meta-analysis (Neumarker, 1997) a broad range of anorexia nervosa-related mortality estimates were found in the literature and the author ultimately settled on a conservative best estimate of 5.9%. Given the incidence rates that we discussed earlier, this would mean that approximately 147,500 people who have the disease today will die of direct or indirect consequences of this disease. If true, this is a frightening death toll.

Although there have been many estimates of the mortality rates for individuals with anorexia nervosa, relatively little is known about whether there are specific demographic or individual characteristics that

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place some anorexia nervosa sufferers at greater risk of dying from this problem. It does seem likely that severity of the disorder at first presentation (Patton, 1988) and length of non-remission of symptoms (Theander, 1992) may predict greater mortality; however, outside these considerations, it is not clear whether there are particular groups of individuals who are more likely to die from anorexia nervosa than others.

Most studies dealing with mortality in anorexia nervosa use a 'historic–prospective naturalistic' methodology (Isager *et al*., 1985) in which individuals who have previously been diagnosed with anorexia nervosa are followed over a period of years to determine death rates. On the basis of this methodology, it is usually reported that individuals who have once been diagnosed as sufferers of anorexia nervosa die at a higher rate. However, such studies rarely provide information as to whether the disease was actually present and active at the time of death.

The current study is an initial attempt to address the question of who dies as a result of anorexia nervosa that is manifest at the actual time of death. It does this by ascertaining the frequency and demographic characteristics of individuals whose death involved current and clinically evident anorexia nervosa as a contributing or causal factor. Using a methodology from similar work (Coren & Hewitt, 1998), to obtain a sufficient number of individuals who died with anorexia nervosa we assessed all of the registered deaths from anorexia nervosa over a 5-year period and from a large geographic area encompassing all of the USA.

Method

The data were collected by the National Center for Health Statistics (NCHS). The 'multiple cause of death' records all death certificates in the USA registered with the NCHS for the years 1986–90, a total of 10,655,721 death records. In addition to its size and inclusiveness in terms of the number of death records included, this data bank includes a great deal of information about the actual causes of and contributors to the death. In each case, the cause of death has been recoded by the NCHS not only to indicate the underlying cause of death, but also to provide a listing of up to 20 conditions clinically present at the time of death (NCHS, 1987a,b). Thus, if the immediate cause of death was cardiac arrest due to malnutrition from anorexia nervosa, anorexia nervosa would be listed as the underlying cause (NCHS, 1987a). Also, if the primary cause was not directly attributable to anorexia nervosa, the condition would have been listed among the secondary conditions if it was detected as being present just prior to, or at the time of, death (NCHS, 1987c). For this study, the sample was chosen in the most inclusive manner possible. This means that any record that mentioned anorexia nervosa either as a primary cause or simply as a condition that was present when the person died was included in the sample. The causes or conditions were based on ICD-9 criteria, which include the basic symptoms of anorexia nervosa (NCHS, 1987a,b) and specifically exclude other possibly confounding conditions, such as feeding problems, loss of appetite of organic or non-organic origin, or other eating disorders.

In order to analyze these data, after selecting all individuals who died as a direct or an indirect result of anorexia nervosa, we split the sample based on either sex or race and calculated rates of death from anorexia nervosa per 100,000 deaths from any factor. We also calculated relative risk. In addition, we plotted the number of deaths by age and sex and determined the number of deaths and rate of deaths from anorexia nervosa per 100,000 deaths from any cause for each decade of age.

Results

A total of 724 records listed anorexia nervosa as a cause or condition of death. The risk of having anorexia nervosa listed as a causal factor was 6.73 per 100,000 deaths and the average yearly death rate was only 145 per year, over the entire USA. This is considerably lower than expected.

Looking at the total sample, some findings were similar to those previously reported for morbidity of anorexia nervosa. First, the sample was predominantly female (78.9%, N=571), with the relative risk of women over men equal to 3.55 (95% CI=2.96–4.23, χ^2=2.19.93, p<0.001). The rate of listed anorexia nervosa on death certificates for females was 11.03 per 100,000 deaths as opposed to 2.73 per 100,000 deaths for males. Caucasian women are at greater risk than Black women (95.1% Caucasian, 3.9% Black) and the relative risk of Caucasian over Black females was 3.42 (95% CI=2.20–5.11, χ^2=35.49, p<0.001). For males the racial distribution followed population percentages (90.8% Caucasian, 8.5% Black) and the relative risk did not significantly favor Caucasians (RR=1.61, 95% CI=0.89–2.72, χ^2=2.37, not significant) on the basis of recent census data (US Bureau of the Census, 1990).

Perhaps the most unexpected findings deal with the age distribution of the anorexia nervosa deaths, seen in Figure 1. Given the predominance of reports of anorexia nervosa onset in adolescence or early adulthood, we expected that the majority of deaths would be among the young. However, for women, the median age of death is 69 years, and for men it is 80 years, suggesting that anorexia contributes to death across the age span and may, in fact, be more closely related to death in the elderly, rather than among adolescents and young adults. This pattern has also been noticed by others (Cosford & Arnold, 1992). Moreover, as can be seen in Figure 1, the

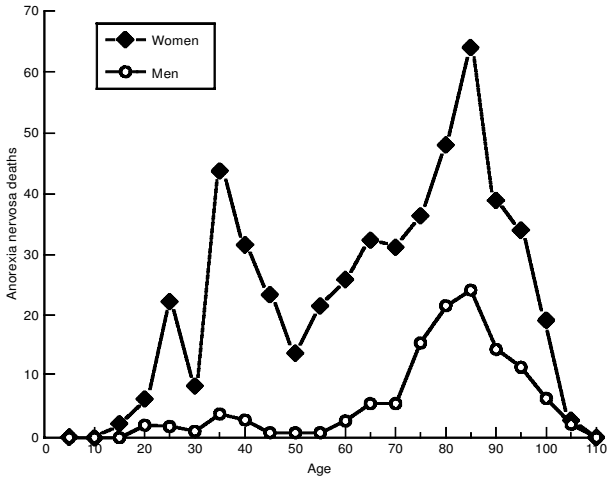

FIG. 1. Age distribution of all NCHS registered death certificates between 1986 and 1990 listing anorexia nervosa as the primary or a contributing cause of death. (Numbers on *x*-axis are the upper boundary of each age group.)

women's distribution shows a bimodality, with a peak at age 35 followed by an ascending rate of mortality with increasing age. For males, only the latter trend, the increased risk among the older population, is apparent.

Table 1 shows the total number of death records which list anorexia nervosa as a causal factor, cummulated over the 5-year period and subdivided by age and sex. It also lists the risk of death by anorexia nervosa per 100,000 deaths per year (using the deaths per age and sex group as the baseline). Note that, by reporting the data in this format, we find that the highest risk of death by anorexia nervosa for females is in the two decades spanning the 15–34 age range, where it is 64.3 per 100,000 deaths. To further put this into perspective, this means that for the approximately 30,598,000 women aged 15–34 years who were alive during the 5-year period surveyed, their actual risk of dying of anorexia nervosa was 0.0000026. For men the risks are considerably smaller, rising to their largest values in the oldest age ranges.

Discussion

This study attempts to provide an initial description of demographic features of individuals who have died as a result of anorexia nervosa. Given the fact that the database used involved over 10 million deaths, and that these included virtually all of the registered deaths in the USA over a 5-year period, it should give us a reasonable picture of the impact of anorexia nervosa as a contributor to mortality. The most striking fact to emerge is that the frequency of death diagnoses that include anorexia nervosa as a factor, whether directly causal or clinically present at any level, is significantly less than would be expected from previous estimates. In women, only 11 instances per 100,000 deaths list anorexia nervosa as a factor, and in men it is only about 3 per 100,000. Furthermore, although some characteristics of individuals in this sample are consistent with prevalence trends in the literature (such as the racial breakdown), several findings are quite inconsistent. For example, the percentage of men who die from anorexia nervosa is more than double the reported prevalence rate of 10%. This might suggest that anorexia nervosa may be particularly lethal for those men who develop the disorder or that the disease is more frequently diagnosed in men upon death.

Although the numbers are surprisingly small, the fact that these data accurately represent the officially reported death rate due to anorexia nervosa cannot be disputed. However, given the low death rate due to anorexia nervosa, that is, low relative to expectations based upon previous estimates, one might be tempted to argue that this may be due to unreliability of the diagnoses on the death certificates, which have led to many unreported cases of anorexia nervosa or unrecognized instances of the disease, especially in young women. To expand this line of reasoning one might further suggest that it is possible that medical examiners are simply not attuned to the disease and are not reporting it. To achieve such a degree of under-reporting of anorexia nervosa as a causal or contributing factor in deaths, however, would require a

TABLE 1. Frequency of risk of death from anorexia nervosa for men and women by decade of age

Age (years)	Females		Males	
	Anorexia deaths (5-year total)	Risk per 100,000 deaths (per year)	Anorexia deaths (5-year total)	Risk per 100,000 deaths (per year)
5–14	2	12.1	1	3.9
15–24	28	62.9	2	1.4
25–34	52	65.0	6	2.7
35–44	56	43.1	4	1.4
45–54	36	16.4	5	1.3
55–64	60	12.2	9	1.2
65–74	69	6.8	18	1.3
75–84	114	7.4	62	4.2
85 or older	154	9.8	46	6.1
Total	571	11.03	153	2.73

massive and widespread degree of ignorance on the part of medical examiners. Hypothetically, let us assume that in one out of every two cases where anorexia nervosa played a role in the death, the anorexia symptoms were not listed on the death certificate. While this would certainly represent an unrealistic margin of error on the part of personnel who fill out the death reports, it would still mean that the number of people who died of anorexia nervosa would remain extremely low. As we noted in the introduction, the expected number of deaths among anorexia sufferers was estimated to be 147,500 based upon current prevalence figures in the literature. Even if we take that as a 10-year cumulative value, our obtained rate of only around 145 per year is still 100 times less than would be expected and if we presume that this is based upon a data bank in which half of all true anorexia-related deaths are misdiagnosed, we remain with an estimate that is 50 times less than expected on the basis of present estimates. Furthermore, one must remember that three-quarters of these recorded deaths involved individuals who were much older than one might expect on the basis of the profile of the anorexia nervosa patient typically reported.

Unreliability in death certificate diagnoses of anorexia nervosa might also be used in an attempt to explain away the counter-intuitive findings of unexpectedly high proportions of older individuals and males in the death records. Again, one might suggest miscodings or misinterpretations of cause of death, presumably due to the incompetence of medical examiners. Several factors suggest that this is unlikely to be the case. To begin with, the ICD-9 and the NCHS instructions for completing death certificates are clear in defining what does *not* constitute anorexia nervosa. For example, there are explicit instructions that rule out simple loss of appetite and any other eating disorder. If we assume that there is an ignorance of the ICD-9 guidelines, we are still presented with a quandary. Recall that the argument for the low reported death rates in young women is supposedly based upon ignorance or failure to look for the symptoms of anorexia nervosa on the part of medical examiners. If that is the case, then it would certainly be illogical to assume that anorexia nervosa would be under-reported in young females, where most practitioners have a reasonable expectation of its appearance, and over-reported in elderly populations, where there is little expectation for it to be present. It is not logical that coroners systematically fail to look for symptoms in a group where the disease is expected (young women) and yet look for and misinterpret symptoms as anorexia nervosa in groups which are widely believed to be virtually immune to the disease (elderly women and men). Logic suggests that, if there was a systematic bias toward under-reporting anorexia nervosa symptoms associated with deaths, then this bias would hold across all demographics.

Returning to the most striking finding in these data, namely the very low death rate associated with anorexia nervosa, we must then ask why studies have suggested high death rates in samples of patients with this problem. The higher death rates reported in the literature previously may well be an artifact associated with the longitudinal or 'historic–prospective naturalistic' methodology (Isager *et al.*, 1985). This methodology involves simply monitoring the death rate in individuals who have previously been diagnosed with anorexia nervosa over a period of years to determine death rates. Once assigned to the anorexia group, few studies bother to assess whether the disorder was in remission or active at the time of death. Our data provide information on deaths where anorexia nervoxa was present at the time of, and a factor involved in, the death. Moreover, if there are co-morbid risk factors associated with anorexia nervosa, then these factors might elevate the apparent death rate, rather than anorexia itself. Such co-morbidity of risk factors does appear to be the case. For example, Striegel–Moore & Huydic (1993) reported that females with anorexia nervosa are twice as likely to be problem drinkers as other women. Krahn (1991) reviewed the literature and found that anorexics had a higher incidence of a variety of substance abuse problems. Furthermore, Braun *et al.* (1994) found that 82% of patients with anorexia nervosa had Axis I diagnoses in addition to their eating disorder. These included (in addition to the substance abuse problems found in other studies) depression, anxiety and personality disorders. Substance abuse and psychiatric problems are common causes of reduced life expectancy; hence it would be expected that people with anorexia nervosa in their history, even if it was no longer an active condition, would have higher death rates due to the co-morbid conditions, even if their eating problem had no effect on their longevity.

The second major result to emerge from these data is that the age distribution was markedly different from expectations based on the usual most common conception of anorexia nervosa. Traditionally, this eating disorder has been viewed as a young woman's problem, with age of onset usually noted in adolescence, perhaps as young as 13 years of age. A number of reports have suggested that there may be late-onset anorexia, or late reappearance of an earlier anorexia that may have been in remission (Cosford & Arnold, 1992; Gowers & Crisp, 1990; Hall & Driscoll; Hsu & Zimmer, 1988). Previously, however, older individuals with anorexia nervosa have been considered rather rare. Because of the predominance of reports of early-onset anorexia nervosa, we expected that the majority of post-mortem diagnoses noting the presence of this problem would be found among the relatively young (Ratnasuriya *et al.*, 1991) according to the data provided by the officially registered death certificates; however, this is not the case. This tends to confirm other recent findings that suggest that anorexia nervosa among the elderly needs to be acknowledged as a manifest disorder (e.g.

Cosford & Arnold, 1992; Gowers & Crisp 1990), although this eating problem in the elderly may have causal factors very different from those of the more intensively researched early-onset condition. Moreover, mortality in the elderly seems clearly greater than in younger people with the disorder. It is not clear why this may be the case. One possible explanation could be that the malnourishment that is experienced with anorexia nervosa taxes the resources of the elderly more than those of younger people. Thus the cardiovascular or other systems of elderly persons may be more compromised by malnutrition. Certainly, this is an important area for future research.

Even though mortality is greater among older individuals in this study, it is the case that the relative risk of dying from anorexia nervosa is greater for younger women. This means that risk from dying from anorexia nervosa, in comparison to all other causes of death, is greater for younger women than for other groups. Although this might suggest that anorexia is a greater problem for younger women than for older women, it must be remembered that the total number of deaths was greater for the older group. The difference in relative risk may simply be due to the fact that there are more causes of death (e.g. diseases, disorders, complications and so forth) in older women than in younger women.

Although there is little written on differences in clinical presentation for elderly versus young individuals with anorexia nervosa, there are suggestions that the clinical picture is very similar, with the exception, of course, that amenorrhea may be due to menopause in women. For example, Cosford & Arnold (1992) reviewed several cases of anorexia nervosa in elderly persons and found that that the elderly patients showed similar psychopathology to that of typical younger individuals with anorexia nervosa, which is consistent with other work on subclinical anorexia nervosa in elderly men (Miller *et al.*, 1991). Moreover, they also found that about half had initial onset of the disorder early on whereas the other half had a late onset after age 50. Likewise, numerous reports (Gowers & Crisp, 1990; Hall & Driscoll, 1988; Hsu & Zimmer, 1988; Riemann *et al.*, 1993) indicate that elderly individuals with anorexia nervosa come to the attention of clinicians following significant stressful events. The elderly can experience significant stressors, such as loss of loved ones, retirement, changes in living situations and so forth, at more frequent levels than younger people. Thus, these environmental events may play a role in exacerbating or initiating an episode of anorexia nervosa in elderly individuals.

Looking again at the data in Figure 1, the bimodality that we observe for women would be consistent with the hypothesis that there are two forms of anorexia nervosa. The first, which we could call *classic anorexia nervosa*, may be characterized by early onset and is predominant among women. For example, by considering all deaths prior to age 45, we find 155 deaths over the 5-year period. Of these deaths, women account for 89%. On an annual basis, this form constitutes a small mortality risk, accounting for about 31 deaths per year, and an aggregate rate of only 16.5 per 100,000, or 0.00017 of all deaths in this age range. Furthermore, at least as listed on death certificates, deaths occurring below the age of 45 involving anorexia nervosa encompass only 21.4% of the total number of anorexia nervosa-related deaths, with the bulk of the deaths occurring in the latter half of life (78.6%). This later form of the disorder, which should technically be called *presbyanorexia nervosa*, still shows a predominance of women; however, men account for a much higher proportion of older anorexics than we find for the classical form. For anorexics who die at age 45 or older, 24.4% are male. For both sexes the age pattern is similar to that for older individuals. Male and female death rates produce parallel curves in the latter half of the life span, and there is a steady increase in mortality due to anorexia nervosa with increasing age. This reaches its peak in the high 80s.

In an attempt to replicate some of the findings in this study, we obtained death record data for the years 1985–96 from the Canadian province of British Columbia (total number of deaths 258,165). The data provided the underlying and contributing cause of death and we selected all individuals who died with anorexia nervosa as an underlying or contributing cause. Like the US data, these data are based on ICD-9 diagnoses. A total of 26 individuals died with anorexia nervosa listed as the underlying or contributing cause death (nine men and 17 women). The risk of death from anorexia nervosa overall was 10.07 per 100,000, compared to 6.67 per 100,000 in the US sample. For women, the risk was 13 per 100,000, compared to 10 per 100,000 in the US sample, and for men 7 per 100,000, compared to 3 per 100,000 in the US data. The median age of this group was 80, consistent with our findings from the US data. In general, the findings are quite similar for the two samples, with both showing low rates of death from anorexia nervosa and for the age level of individuals dying from anorexia nervosa.

Overall, this study provides descriptive and demographic information on individuals whose death certificates indicate that they have died with anorexia nervosa as either the primary or a contributing factor. The results suggest that, consistent with expectations based on prevalence data, significantly more women die from anorexia nervosa than do men, although the ratio of women: men changes among older individuals. The pattern of the data suggests that there may be two fatal forms of the disorder, one that impacts mainly younger women, and a second form that appears considerably later in life and affects women and men in a 3:1 ratio. The results suggest that beliefs about sex and age distributions in fatal anorexia nervosa may require re-examination.

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