Perspective

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Mortality rates for pediatric rheumatology patients significantly lower than previously reported

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Introduction

A recent study by researchers from the Cleveland Clinic found that the overall mortality rate in the U.S. for all pediatric patients with rheumatic diseases was not worse than the age and sex-adjusted population. Furthermore, mortality rates were significantly lower than reported in previous studies of rheumatic diseases and conditions that are associated with increased mortality [1].

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) estimates that 300,000 children in the U.S. suffer from some form of arthritis or rheumatic disease. According to CARRA, childhood arthritis is the #1 cause of acquired disability in children and is the 6th most common chronic childhood disease.

While rheumatic diseases present well-known risks to health, function, and quality of life, several conditions-juvenile rheumatoid arthritis, childhood systemic lupus erythematosus, dermatomyositis, various vasculitides, and systemic sclerosis are associated in various studies with a small but significant increase in mortality [2].

Description

The Cleveland Clinic study team, however, maintains that previous mortality studies were relatively small, reported mortality outcomes only on specific diseases, had a follow up time of less than 10 years, and were mostly conducted prior to the 1990s, when new and improved drug treatments emerged [3]. The team suggests that larger studies may also be flawed because most were based on physician surveys, without strategies to verify response.

To determine the mortality rates, risks, and causes of death associated with pediatric rheumatic diseases in the U.S., the researchers examined the world's largest rheumatology registry, the Pediatric Rheumatology Disease Registry (PRDR), which includes 49,023 patients from 62 centers who were newly diagnosed between 1992 and 2001. Identifiers were matched with the Social Security Death Index censored for March 2005 [4]. Death certificates, referring physicians, and medical records confirmed deaths. Causes of death were derived by chart review or from the death certificate.

After excluding patients with malignancy, 110 deaths were identified among 48,885 patients in the PRDR registry. This number was significantly lower than the expected mortality from the age-and sex-adjusted U.S. population especially among 18,111 patients who were followed up for at least 9 years. The standardized mortality ratio was notably greater for systemic lupus erythematosus and dermatomyositis but not for systemic juvenile rheumatoid arthritis and was markedly less for pain syndromes. Most of the deceased with inflammatory disease died of their disease or disease complications, while many of the deceased with pain syndromes died of non-natural causes [5].

Conclusion

One possible cause of the increased survival in the present study compared with previous studies may be the improved treatment that was introduced in the 1990s, said the lead author of the study. Since the information in the PRDR was limited, we could not explore

in depth for risk factors or early predictors of mortality. This and continued follow-up of this cohort for mortality trends should be investigated in future studies.

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