The social circumstances surrounding progressive muscular dystrophy

Yuji Sasaki,C.I.

Tokushima National Hospital, National Hospital Organization, 1354 Shikiji, Kamojima, Yoshinogawa, Tokushima 776-8585 Japan

Received 2 February 2012 ; received in received from 25 February 2012 ; accepted 2 March 2012

1.The changes in muscular dystrophy wards

The acceptance of muscular dystrophy patients to national sanatoriums began in 1960. "A progressive muscular atrophy measures summary" was devised in 1964. By the attendance at school investigation of 1965, 67.1% of muscular dystrophy children obtained temporary exemption from enrollment at school. Although 15.1% of patients went to schools for disabled children, it was necessary for a parent to accompany them. National sanatoriums accommodated the patients, and it subsequently became possible for patients of school age to receive education. This medical system did not watch cases in the world. In the muscular dystrophy ward, 100 beds in total were prepared in 10 institutions in 1964. Applications for hospitalization of patients increased, and the hospital bed capacity rose to 2020 in 1970. Occupational therapy aiming at "a definite aim" and "specialty improvement of work technology" was given for patients who were over school age in 1975. A move to support home care patients occurred subsequently. A daycare ridge was made available in each sanatorium from 1976.

2. The problems of muscular dystrophy wards

In muscular dystrophy, respiratory failure and heart failure are the most common causes of death [1]. Artificial respiration therapy came to be provided for respiratory failure in national sanatoriums throughout the country from the late 1970s. The initial artificial respiration therapy was outside the body expression breathing. Intermittent positive pressure-style artificial respiration therapy (IPPV) began subsequently. NIPPV was performed as noninvasive artificial respiration therapy from about 1990. The average life span of patients with Duchenne muscular dystrophy was 20.4 years in the 1980s. In 2004, the average life span increased to 31.0 years for patients wearing respirators [2]. The hospitalization of muscular dystrophy ward inpatients was therefore extended to approximately 25 years from approximately ten years [3]. When the 1990s began, respirators began to be used for home care patients [4]. The number of patients admitted to the national sanatoriums decreased, and the patients who lived in the area increased. The incidence of new patients decreased as a result of genetic counseling and genetic screening. In 1999, the proportion of patients who received artificial respiration management in a muscular dystrophy ward became 38%. As a result, aging and the aggravation of the inpatient advanced. Medical therapy and management of water and the motor are carried out for heart failure [5]. For digestive function disorders and nutritional disorders, canalis nutricius by gastric fistula enlargement began. As for the Tokushima National Hospital muscular dystrophy inpatients, the average age was 45.9 years old in 2010. The proportion that received artificial respiration

Correspondence to: Haruo Taichi, P.T., Tokushima National Hospital, National Hospital Organization, 1354 Shikiji, Kamojima, Yoshinogawa, Tokushima 776-8585 Japan. Phone: +81-883-24-2161 Fax : +81-883-24-8661

management increased to 62%. The average age of at-home muscular dystrophy patients was 26.9 years. The proportion that received artificial respiration management was 70%. It will become a problem in future that a care power is short by the aging of patients oneself and the family.

Reference

1. Ishihara T. Management of Patients with Duchenne Muscular Dystrophy. Brain and Development. 36: 130-135, 2004.
2. Konagaya M. Muscular dystrophy. The present and the future. Social medicine and a change of the quality of life. Clin Neurosci2008; 26: 200-2001.
3. Miyosi K. The outcome of the patients admitted to the muscular dystrophy ward 20 years ago. 61: 49-51, 2007
4. Tatara K, Fukunaga H, Kawai M. The present conditions of the muscular dystrophy medical care in the national hospital mechanism. Iryo 2006; 60: 112-118.
5. Saito T, Kanno S. How We Have Treated and Cared for Patients with Duchenne Muscular Dystrophy and Severe Congestive Heart Failure. (In Japanese) Brain and Development 2005;37:281 -288