

An action to the working model construction of the muscular dystrophy patients

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Abstract

Two 19-year-old patients with Duchenne muscular dystrophy and a 30-year-old patient with Becker-type muscular dystrophy participated in working model construction and homepage production to enable web accessibility. Through a correspondence course using the learning program of a working support institution, all the patients were able to obtain knowledge and use the system without difficulty. Full-scale working activity will be carried out in the future. However, the daytime activity of disabled individuals with very severe disorders is candidates for the care. There is a problem to be resolved in that it is difficult to obtain a labour reward while receiving working continuation support payment.

Key Words: Duchenne muscular dystrophy, Becker-type muscular dystrophy, homepage production, web accessibility, PC

Background

Because the independence of activities of daily living (ADL) is required for a disabled person to work in Japan, such work is difficult. In recent years, the need to train staff in vocational rehabilitation has been emphasised to promote the employment and social participation of the disabled. Vocational rehabilitation staff members play the following roles for the disabled and to promote acceptance: work training, consultation correspondence, the reclamation of the employment company, consciousness reform of companies, and support after working. The "physically handicapped person employment promotion law" was revised to the "law for the promotion of the employment of handicapped persons" in 1987. Vocational rehabilitation-related services were made compulsory by this revision. In addition, as a concrete practice to organise vocational rehabilitation duties, occupation centres for the disabled were set up. This provides vocational rehabilitation for the disabled and supports their independence and social participation. On the other hand, the handicapped person independence support law became enforced as a result of the reorganization of the handicapped person health

service system that was carried out in 2006. This law revision stipulates that the independence in the area is planned at a part of the social welfare underwork reform as a basic idea. The issue of working is one of the most important areas. It is necessary when determining the working support required by a disabled individual to consider factors such as his or her character, interests, and general ability. The enforcement of vocational rehabilitation that rolled up an area is necessary. The vital prognosis of the muscular dystrophy extended by the wearing of progress and the respirator of the care drastically. Duchenne muscular dystrophy is the most common form of muscular dystrophy, and severe early aggravation can occur.

However, the vital prognosis of the disease has improved remarkably. After graduating from a school for disabled children, the patients think about how they will live from day to day. However, an employment rate of 18% in private enterprise has not yet been accomplished. Through the handicapped person independence support law, daytime activity support of people severely affected by the disorder is behind with measures. This is because when there is a defect in the most severe cases, the daytime activity is targeted for the care, and the activity that did that we work with the

subject cannot be performed. The Association of Japanese Muscular Dystrophy will run a disabled person health welfare promotion business as a business promoted by the Ministry of Health, Labour, and Welfare from 2007. It was found that the will to work of the muscular dystrophy patients (patients with Duchenne muscular dystrophy in particular) improved as a result and that the medical treatment environment was improved, according to the working papers by med-tech progress, and that the average lifespan was extended. Furthermore, in muscular dystrophy patients for whom symptoms gradually change, it is necessary to assign a place adapted to improving muscular strength, unlike the working conditions for other disabled persons. In addition, it is necessary to progressively refine the system after a trial because it is difficult for companies and groups to adapt to the working system immediately. A trial model was performed in 2008. Tokushima Hospital was chosen to be the trial model development institution.

Purpose

Generally, the kind of labour that can be offered is important when we think about working. For muscular dystrophy patients this is particularly important and some demand for this labour is required. When we think about the work of muscular dystrophy patients, a PC is an indispensable tool. In our hospital, business card making / postcard making / poster making was previously undertaken as a working activity using PCs. However, the requests for these products decreased year by year because of the recent spread of PCs and printers. As such, it became necessary to add a technique that no commercial homepage making exists in the production of the homepage softly. In recent years, web accessibility has attracted much attention. This is the technique by which elderly and disabled people can acquire information and send it to web pages.

Methods

There were no suitable staff members in the hospital to conduct the working activity because the production of a homepage requires a certain expertise. Therefore, cooperation with the "working support centre harmony" to produce a homepage suitable for web accessibility was undertaken in Tokushima. Disabled individuals were scheduled to

receive a correspondence course using the internet from the institution. The teaching materials used in the learning program that was prepared were provided on a web page. In addition, it was decided that the harmony staff would come to the hospital once for two weeks and initially conduct visit guidance with a correspondence course for six months. This was performed at the workplace using one of the space wards. The enforcement situation was conveyed by internet communication using a webcam at the start and end of work. The nursing guidance room staff conducted maintenance of motivation or understanding of the work situation.

Results

Two 19-year-old patients with Duchenne muscular dystrophy and a 30-year-old patient with Becker-type muscular dystrophy participated in the project. Through the correspondence course using the learning program, all the disabled individuals were able to cultivate knowledge and use the system without difficulty. For these disabled individuals, it was found that the required social manner or ability to fulfil job responsibilities for working was missing. In this system, the daytime activity of disabled persons with very severe disorders is candidates for the care. There is a problem in that it is difficult to obtain a labour reward while receiving working continuation support payment. With the cooperation of harmony, full-scale working activity will be carried out in future, once this problem has been resolved.

Discussion

It was difficult for the muscular dystrophy patients to practice full-scale working activity in medical facilities. Therefore, the cooperation of the institution is required except that the working support of the handicapped person is taken. Furthermore, it is necessary to perform advice and guidance continuously to enable a social life to be obtained through working activity because muscular dystrophy patients have extremely few opportunities for education and social participation. Owing to the fact that this working activity involves internet communication, enforcement is possible for home-care patients. In addition, patients for whom symptoms change can continue their working activity in bed. It is thought that this working activity has to focus more on practice on examination.