

In 2014, the Japanese Ministry for Health, Labour, and Welfare commissioned a national patient survey of ME/CFS patients in Japan. The following article by Japan ME Association president Mieko Shinohara (originally published in Japanese in the July 2015 issue of *Normalization*) summarizes the survey results, which revealed that 30% of ME/CFS patients in Japan are severely ill patients.

ME/CFS Patient Survey Report: Ministry of Health Survey Reveals Harsh Reality of ME/CFS Patients in Japan

By Mieko Shinohara

1 Introduction

ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome) is a complex, multi-systemic chronic disease that affects the brain and central nervous system. The disease affects the entire body, and as with other serious diseases such as cancer, heart disease, and AIDS, ME/CFS causes significant declines in patients' quality of life. Central characteristics are central nervous system-related abnormalities and autonomic dysfunction. It is commonly known in the United States and Europe that disease onset most often results after an acute viral infection. The disease is classified as a neurological disorder (ICD-10-G93.3) in the World Health Organization's International Classification of Diseases.

The International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME) has estimated that 25% of ME/CFS patients are severely ill patients who are bedridden or nearly bedridden and are only rarely able leave their homes. Further, the Canadian Consensus Criteria for ME/CFS document, supported by international scientific associations and by patient associations in the United States and Canada, notes that 0-6% of adult patients recover to pre-illness physical functional capacity levels. There was a concern that the situation of patients might be similar in Japan.

2 The Ministry of Health, Labour, and Welfare's 2014 Patient Survey on the Daily Living Difficulty Levels of ME/CFS Patients

Past surveys of ME/CFS patients conducted in Japan were limited to assessing patients who were able to travel to medical facilities for regular visits. No previous survey had shed light on the daily living difficulties of severely ill patients. It is extremely rare for ME/CFS patients to be able to obtain Physical Disability Certificates, and nearly all government disability benefits remain inaccessible to them.

Our association had sought a survey of severely ill ME/CFS patients since 2010, and we submitted a petition to the 2013 extraordinary Diet session requesting that a national patient survey be conducted. In 2014, the Ministry of Health, Welfare, and

Labour commissioned the “Patient Survey Concerning Activities of Daily Living Difficulty Levels of Chronic Fatigue Syndrome Patients” to the St. Marianna University School of Medicine. The survey results were submitted in a report to the government in March 2015.

The survey examined patients’ difficulties with daily living activities and the factual circumstances surrounding their diagnosis and treatment. The resulting data will serve as an important foundation for future policy considerations regarding the improvement of patients’ quality of life, meeting of public disability assistance needs, and improvement of medical care. Conducted between August 2014 and February 2015, the survey was not limited to severely ill patients, but encompassed patients with mild, moderate, and severe levels of disease who had been diagnosed with ME/CFS at a medical facility.

To address the difficulties of assessing severely ill patients who are unable to visit medical facilities for regular treatment, a widespread call for participation was made through medical facilities, via online and print media announcements as well as through the patient association. Data was also gathered through oral questioning carried out in home visits and in phone calls. Of the 251 total patients assessed, 56 patients were male (22%), 195 were female (78%), and the average age was 41.8 years old.

The survey used the Performance Status (PS) Scale (see table below) to classify disease severity in ME/CFS patients based on their physical capacity according to the Scale. For analysis purposes, the survey classified participants into three severity groups: PS value 0-5 (mild level disease), PS value 6-7 (moderate level disease), and PS value 8-9 (severe level disease) (see Appendix). For items for which a comparative statistical analysis was possible, data for the three severity groups were compared.

3 The Serious Condition of ME/CFS Patients in Japan

The survey revealed that 30.2% of ME/CFS patients had severe level disease (PS value of 8 or 9). The IACFS/ME estimates that severely ill patients comprise 25% of ME/CFS patients. The Ministry of Health survey results indicate that a similar situation exists in Japan. Further, patients with moderate level disease accounted for a further 35.1%, underscoring the large number of patients for whom daily living is extremely difficult.

Nearly 70% of patients responded that they were unable to perform housework or could perform only a little housework. Many such patients are likely to require home nursing assistance. Even among patients with so-called mild level disease, 86.9% responded that symptoms worsened after doing housework, with 44.6% requiring more than 24 hours for recovery, sometimes becoming bedridden. The findings indicate the serious nature of patients’ impairment in their ability to perform activities of daily living and strongly suggest the need for home nursing assistance in many cases.

For patients who were unable to perform housework, 53% responded that their mothers did their housework, with 25.1% of patients' fathers, children, or siblings and 33.9% of spouses doing patients' housework. Family assistance was indispensable for the daily living needs for the majority of patients. The average age of patients was relatively young at 41.8 years old, an age at which living assistance from family members may still be available. But as such family members enter old age and are no longer able to provide personal care for their adult children, home nursing assistance will be urgently needed. 43% of the severe level disease patients were unable to walk 10 meters without worsening symptoms, an indication of the severe degree of impairment in their ability to conduct daily living activities.

76.7% required complete bed rest after attending doctor visits. Recovery times ranged from 0.5 to 1 day at the shortest to several days to weeks; the average recovery period was 8 days. In one case, a patient became bedridden for four months. Patients who reported that they were "mostly unable" to leave their homes other than for doctor visits (40.2%) or "completely unable" (6.6%) comprised 46.8% of patients, with 85% of severe patients and nearly 50% of moderate patients mostly housebound other than for doctor visits. The findings revealed another reality of the disease: patients' social isolation resulting from their inability to participate in normal societal life.

While 81.6% (excluding those who were school age or pursuing studies at disease onset) were employed at the time of disease onset, 50% of patients quit work immediately or were forced to quit following a leave of absence. Of the patients who remained employed, 8.4% were on a leave of absence, 10% were forced to change the substance of their work, with only 5 patients (2%) able to continue with their original employment.

The survey results also suggested that, based on patient surveys for other neuromuscular diseases designated as intractable diseases using a different performance scale to assess impairment (with meals, nutrition, and breathing according to the modified Rankin scale), 90% of severe ME/CFS patients, 30% of moderate patients, and 10% of mild patients would be eligible for government medical expense assistance. Patients who required the size or shape of food to be altered for them in order to eat comprised 30%. There was one patient who was only able to obtain nutrition through IV infusions administered at the patient's home.

4 Patients Are Unable to Exercise Fundamental Rights

24.3% of ME/CFS patients were attending school at the time of disease onset, with those under 20 years old (9 elementary school students, 8 middle school students, 21 high school students, 10 university or vocational school students) comprising 19.1% of patients. 42.6% of these patients were able to continue their education in some form, while nearly 60% were unable to continue. Of the 17 patients who were of compulsory education age, only 2 patients were receiving special assistance education, with 6 students responding that they were unable to attend school. The survey thus revealed that these students' rights to a compulsory education were not being protected.

Of the 118 patients who had the right to vote who responded to questions by phone and through home visits, only 35 patients (29%) were able to exercise their right to vote. The average PS value of patients who were unable to vote was 6.2, with severe patients the most affected.

5 Voices of ME/CFS Patients

The top reason for triggering a worsening of symptoms (identified by 70% of patients) was “circumstances that make over-exerting myself unavoidable.” Examples of such circumstances included: “I must do the housework even if it exceed my limits,” “I must work for financial reasons,” and “My workplace (or school) will not accommodate my illness.” Patients identified “unbearable physical symptoms” as the most difficult aspect of living with the disease, highlighting the severe physical suffering experienced by patients. Other serious problems included the lack of specialist doctors, social isolation, financial hardship, and the lack of understanding about the legitimacy of the disease from others.

The most urgent action sought by the government was medical research, followed by “recognition of the legitimacy of the disease,” “medical expense assistance,” “access to welfare services,” “access to disability pensions,” and “changing the disease name.”

Patients who sought medical expense assistance strongly emphasized the out-of-pocket costs of nutritional supplements and alternative medical treatments that are not covered by health insurance. Their dependence on family members to cover these costs affect family income situations. We can infer that patients’ opinions on this issue were driven by their serious concerns for their family financial situations.

6 Towards a Disability Assistance Structure Commensurate with Actual Disability Levels

A new law for patients with intractable diseases was established in 2014, with the number of diseases expanded to 300 diseases. However, ME/CFS was excluded from the Act for Comprehensive Welfare of Persons with Disabilities and from diseases eligible for medical expense assistance for the reason that Japan does not currently have diagnostic criteria for ME/CFS that includes objective disease markers (a prerequisite for inclusion in the law).

The serious state of ME/CFS patients revealed by the Ministry of Health survey point to a need for a fundamental shift to a disability assistance structure that is based on the actual severity of patients’ physical impairment, rather than exclusion based on a disease name or patient population size. ME/CFS patients are suffering daily from being mired in this “chasm in the system” of Japan’s disability assistance law. Changes to the existing system will soon allow ME/CFS patients to be able to live their lives in hope.

Appendix:

Performance Status (PS) Scale for Daily Living and Working

- 9: Unable to perform personal care; requires constant nursing care; bedridden
- 8: Able to perform some degree of personal care; requires some nursing care; bedridden for more than 50% of the day
- 7: Able to perform personal care and does not require nursing care, but unable to participate in normal societal life; unable to perform light labour
- 6: Able to perform light labour on good days, but requires rest at home for more than 50% of the week
- 5: Participation in societal life is difficult. Able to perform light labour, but requires rest at home several days of the week
- 4: Due to debilitation, unable to work or participate in normal societal life several days a week, requires rest at home
- 3: Due to debilitation, unable to work or participate in normal societal life several days a month, requires rest at home
- 2: Able to participate in normal societal life and able to work, but requires rest from time to time due to debilitation
- 1: Able to participate in normal societal life and able to work, but feels debilitated from time to time
- 0: Able to live a normal life without debilitation and to act without restrictions