

Research on Current Status of Work Difficulties according to Symptoms of Intractable Diseases and the Elements of Work Supports

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Intractable Diseases Policy, Reasonable Accommodation, Support for the Balance between Medical Treatments and Work, Disability in Employment Settings, Inter-sectional Cooperation between Medical and Labor

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This research revealed that the symptoms characterized as "instable physical condition including general fatigability" commonly seen regardless of kinds of diseases, was dominant factor of work difficulties caused by intractable diseases, although some other stable disease-specific symptoms existed. This research also revealed that the effective employment supports included suitable job selection, in which recovery from fatigue and health maintenance were secured in terms of working hours, rest and holidays, while being able to demonstrate his or her ability reasonably without overstrain. Also of importance was promoting reasonable accommodation in a workplace in order to achieve a good balance between medical treatment and work.

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2 Research Period
FY2013 to 2014

3 Composition of the research report
Chapter 1: Background, Purpose and Methods
Chapter 2: Employment Difficulties due to Symptoms of Intractable diseases and Effective Supports (Research Results)
Chapter 3: Discussions of the Research Committee
Materials at the end of report

4 Background and Purpose of Research

Advancement of medical treatments for intractable diseases is enlarging the employability for persons with intractable diseases, who used to be difficult to work. Employment supports specialized for intractable diseases are increasingly needed, especially for those have willingness and ability to perform their duties required by employers, but have specific difficulty because of intractable diseases. In this regard, it is important to consider the levels of the symptoms of intractable diseases, in addition to conventional consideration of types of disease or disability certificates. This research, by conducting a questionnaire survey to persons with intractable diseases covering the widest possible range of diseases, aims to understand a variety of symptoms, their levels and impairments unique to each disease, and the current status of consequential work difficulties, and determine the necessity of work supports in workplaces and community.

5 Method

(1) Research Committee

A research committee was settled composed of academic experts regarding employment support for persons with disabilities, some representatives for patients of intractable diseases, for employers, for the Intractable Diseases Consulting and Support Centers, for medical doctors, for industrial physicians, for occupational health nurses, for medical social workers, for vocational rehabilitation, and government officers. The agenda included a plan, implementation and analysis of the survey, work supports resolving the specific work difficulties of intractable diseases, and application of research results, in conjunction with the national deliberation on the criteria of the levels of symptoms of intractable diseases.

(2) Literature Review

As a preparation for the survey, before or along with the national deliberation on the criteria of levels of symptoms during 2015, we reviewed and organized the symptoms of each disease, which would affect workability (e.g. fatigue, pain, skin disorders, immune dysfunction and vulnerabilities of physical functions) including those not certified by the current physical disabilities criteria, according to published diagnostic criteria.

(3) Questionnaire Survey to Persons with Intractable Diseases

Based on the literature review, we conducted a questionnaire survey for persons with intractable diseases in cooperation with associations of intractable diseases patients and support organizations. The levels of symptoms were determined as possible by the criteria of severity of each disease. The contents of the survey were structured for numerical analysis to identify the characteristics of "symptoms of intractable diseases," "work difficulties" and "effective supports", based on the latest concept of disabilities to model the relationships among them, premising a great

impact of job requirements and workplace accommodations on work difficulties and needs for work supports.

- "Symptoms of intractable diseases" includes "physical and mental functions" involving those not certified as disabilities, or "health conditions" which could affect "activities" and "participation." It also includes consequence of types of diseases, levels of symptoms and certificated impairments.
- "Work difficulties" means difficulties and problems of specific "activities" and "participation" the person experiences before and after starting work. It is influenced not only by "symptoms of intractable diseases" but also various environmental and personal factors. Also, "disability in employment settings" is defined as "work difficulties" related to "health conditions."
- "Effective supports" refers to systematized supports and accommodations including various environmental and personal factors, which resolve or reduce "disability in employment settings" caused by "symptoms of intractable diseases," adjusted by other factors such as gender and age. It involves selection of job (e.g. job category, employment condition and physical burden), workplace accommodations, and usage of supports and service providers.

6 Results of the Survey

(1) Execution of the survey and the response rate

Among 110 diseases designated the Intractable Diseases Act enforced in 1st of January 2015, the survey covered diseases of which related patient groups could cooperate with the survey. Among 5,789 dispatch, 2,439 patients responded with a wide range of diseases including of blood, autoimmune, endocrine, nervous system, eye, cardiovascular, digestive, skin and connective tissue, born and joint, kidney and urinary organs (the reply rate was 42.1%).

Among the working-age respondents, those currently working was 54.2% (including 3.0% taking a sick leave). 61.5% of the unemployed persons were housewives and students. Nervous system diseases such as Parkinson's disease were the main factor of unemployment due to medical treatments. The most common disease people actively seeking work was Crohn's disease, which was 10%. While the unemployment rate was 5.1%, if people not seeking jobs were included, the percentage of the people who were willing and able to work, but not working was 16.9%. The job seekers' major preferred job condition was full-time and part-time works, both at the same extent.

Among the total number of respondents, 71% have had working experience with intractable diseases in the last 10 years (the largest group was of those with inflammatory bowel disease and autoimmune disease). 32% had left jobs in any relation to intractable diseases (the largest was of those with nervous system disease such as Parkinson's disease). 55% had sought jobs with intractable diseases (the largest was of those having neurofibromatosis and Crohn's disease), and 45% had succeeded in employment or re-employment (82% of the job seekers).

(2) Characteristics of Symptoms of Intractable Diseases

The common characteristics of symptoms and impairments among intractable diseases as chronic disease were found as ①instable physical condition including general fatigability, ②uneven occurrence age, either underage or after middle-age, ③declined concentration and vitality, and ④difficulty of dealing with the physical instability.

Some diseases had impairments conventionally certified as disabilities (e.g. physical motor, visual, or internal impairments), while others had not (e.g. visual field defects, nyctalopia, amblyopia, polyopia, skin impairment or changes in appearance).

An Instable physical condition including general fatigability

Weekly, daily or longer-term changes in physical conditions caused severe social hindrances due to fatigability or declined stamina. A little overstrain tended to

collapse health conditions or accelerate the progress of disabilities. It led to medically-imposed restrictions at work. This characteristic was common regardless of diseases, either with or without certified disabilities, having a close relationship to the length of hospitalization and irregular ambulatory visits, and the work prohibition imposed by a doctor.

B Uneven occurrence age, either underage or after middle-age

Uneven occurrence age included the early-age occurrence of cardiovascular disease and neurofibromatosis, or the older-aged occurrence of nervous system diseases and bone and joint diseases.

C Declined concentration and vitality

Declined attention, concentration, memory, vitality, motivation and/or clarity of speech were identified in the diseases such as endocrine, nervous system, bone and joint diseases.

D Difficulty of dealing with the physical instability

The conditions where it was difficult to predict the change in physical conditions or deal with such change, were seen in a certain number of patients with a variety of diseases, and were related to a number of irregular ambulatory visits.

E Impairments certified as disabilities

Physical motor impairment, visual impairment, internal impairment

F Disease-specified impairments not certified as disabilities

- Eye diseases: visual field defects, nyctalopia, amblyopia
- Skin and connective tissue diseases: skin impairment or changes in appearance

(3) Difficulties in "Work Preparation and Transition" related to the symptoms, and effective supports

The symptom of "instable physical condition including general fatigability" was closely related to the difficulty of "lack of confidence to maintain a good balance between medical care and work," "unemployment" and "disturbance in education, training or career selection." In addition, the symptoms such as "decline in vitality and motivation," "difficulty of dealing with the physical instability" and "changes in appearance and looks" were also closely related to the difficulty of "no confidence to maintain a good balance between medical care and work." Also, "the work prohibition imposed by a doctor" had a close relationship to "unemployment."

The important supports for the work preparation and transition were found to include primarily "work consulting and supports provided by a doctor" such as a doctor's advice and notes at the beginning or return to work. Also effective were the patients' organizations' information provisions on work supports for persons with intractable diseases. "Occurrence of diseases at the ages of 13-18" was particularly related to the difficulty of "disturbance in education, training or career selection." Doctor's work consulting was also effective against the difficulty.

(4) Difficulties in "Job Seeking Activity" related to the symptoms, and effective supports

The present research showed that more than 80% of the job seekers had gained a job. Therefore, getting a job itself was not found to be extremely difficult. However, the difficulties of "job seeking activity" were comprised of "difficulty of appropriate explanation on diseases and requesting for the accommodation," "difficulty to get a chance of job interview," "difficulty of showing one's will and contribution to work," and "not able to get a job." And our stepwise multiple regression analysis revealed strong relationship between the symptom of "instable physical condition including general fatigability" and the difficulty of "applying for the opening and conducting a job seeking activity," among relationships between the difficulties, symptoms, accommodations and supports, or other contextual factors (environmental and personal).

Moreover, the symptom of "vulnerable health conditions collapsed with a little

overstrain" had a great impact on "difficulty of appropriate explanation on diseases and requesting for the accommodation," and was related to the "difficulty to get a chance of job interview." Also, "changes in appearance," "serious anemia" and "amblyopia or visual field defects" caused the difficulty of "applying for the opening and conducting a job seeking activity." "Skin disorders," "progressive disease condition" and "declined vitality and motivation" were also related to the difficulty of explanation to companies.

The following supports were found to be effective against these difficulties.

- Promotion of companies' understanding and accommodation during recruitment process (resolution of misunderstanding and prejudice, companies' initiative during the recruitment process to understand necessary accommodation assuming employment, and accommodation for a flexible appointment for an interview).
- Building ongoing consulting support system for both the persons and companies in need through employment period.
- Interests and strength based vocational consulting at the Public Employment Security Offices and Vocational Rehabilitation Centers to help job seekers conducting the activity focusing on their vocational ability and contribution to a company. Vocational training and preparatory supports for qualifying examinations.
- Provision of comprehensive information on work supports for persons with intractable diseases.

(5) Difficulties in "Employment Status and Workplace Adjustment" related to the symptoms, and effective supports

To the difficulties in employment status and workplace adjustment, influence from the symptoms, accommodation and supports, and other environmental and personal factors was identified using stepwise multiple regression analysis, in each difficulty of the main components including issues of "clerical work," "relationships and stress in a workplace," "balance between rest, health maintenance and ambulatory visits and work," "dissatisfaction regarding working condition," "transport and driving," "conflict between health management and work," and "leaving a job (mainly part-time job)."

The symptom of "instable physical condition including general fatigability" was strongly related to issues of "clerical work," "relationships and stress in a workplace," "balance between rest, health maintenance and ambulatory visits and work," "dissatisfaction regarding working condition" and "transport and driving," and also related to "leaving a job in relation to intractable disease."

The symptoms such as "tremor," "declined fluency of speech," "joints pain" commonly seen in nervous system diseases or autoimmune diseases, "declined attention and concentration" and "upper limb impairment" were closely related to the difficulty of "clerical work." The symptoms such as "declined fluency of speech," "change in appearance," "declined vitality and motivation" and "hearing impairment" were related to the difficulty of "relationships and stress in a workplace."

The effective supports for these symptom-related difficulties were "workplace accommodation for ambulatory visits, rest and reasonable workload" and "vocational assessments on ability/disability," in order to promote arrangements of job tasks and work conditions, such as "keeping a sufficient holiday for fatigue recovery and hospital visits," "flexible business adjustment according to health conditions," "no overtime work," "flexible rest" and "works and duties without physical overstrain." In this regard, "companies' understanding and accommodation in the recruitment process" was also effective.

Likewise, the difficulty in "relationships and stress in a workplace" was effectively alleviated by "promotion of disease awareness in managers and colleagues in a workplace" and "adjustment of work responsibility base on one's strength rather than one's weakness." Also, supporting return-to-work from both a doctor and em-

ployer's side during a sick leave was eventually effective to avoid an overstrained work and resolve an issue of balance between medical care and work. Moreover, "job structure premising the unstable work performance due to health conditions" and the "adjustment of work responsibility base on one's strength" were effective for resolving the problem of "conflict between disease management and work."

(6) Difficulties in "Resignation related to Intractable Diseases" related to the symptoms, and effective supports

To the difficulties in resignation related to intractable diseases, influence from the symptoms, accommodation and supports, and other environmental and personal factors was identified using stepwise multiple regression analysis, in each difficulty of the main components including issues of "feelings of alienation and isolation after leaving a job," "leaving a job because of worsen health conditions," "leaving a job because of a conflict between medical care and work," "recommended retirement or discharge in relation to intractable disease," "declined motivation for re-employment after leaving a job," and "expiration of sick leave or discontinued contracts."

Symptoms such as "prohibition of employment imposed by a doctor because of anemia, syncope, heart palpitations and declining immunity," "concern of the progress of a disease condition" and "muscle weakness" were strongly related to "leaving a job because of worsen health conditions." This kind of resignation was effectively prevented by such supports as the "adjustment of work responsibility base on one's strength," "consideration at a business meeting in a workplace about accommodation and adjustment" and "working environment with flexible business adjustment and sufficient holidays," which, in turn, were effectively promoted by "confirmation of doctor's opinion on one's workability and restriction" and "consultation at Assistance Department of Public Employment Security Office."

The symptom of "declined energy and fatigue" was strongly related to "leaving a job because of a conflict between medical care and work," which was effectively prevented by "disease and disability awareness among managers and colleagues in a workplace" and "confirmation of doctor's opinion on workplace restriction."

The symptom of "declined concentration and attention" was strongly related to "recommended retirement or discharge in relation to intractable disease," which was effectively prevented by "preventative rest or leave at an early stage of health worsening."

The symptoms of "increased irregular ambulatory visits" and "tremor and gait disorder" were strongly related to resignation due to "expiration of sick leave or discontinued contracts," which was effectively prevented by "accommodation of working hours for ambulatory visits."

Moreover, the "declined motivation for re-employment" and "feelings of alienation and isolation" after leaving a job in relation to intractable disease might have caused the difficulties in "work preparation and transition," initiating a vicious circle. As the supports during employment such as "workplace accommodation," "doctor's work consulting and supports" or "work support providers' individual consultation and advice" were effective to prevent the "declined motivation for re-employment" and "feelings of alienation and isolation" after leaving a job, those supports could also be preventive supports for "work preparation and transition."

6 Discussions and Conclusion

(1) Consideration on the Results

This research revealed the characteristic symptoms of intractable diseases typified by "instable physical condition including general fatigability" regardless of kinds of diseases, although some other stable disease-specific symptoms existed. Also, it was revealed that, because of this instability, although many persons with intractable diseases were able to work normally when their health condition was fine, nevertheless it was important for them to work in such condition as flexible break or leave in case of worsen health condition or adjustable work responsibility. Moreover,

in order to prepare such accommodation during employment, it was found to be important to clarify the necessity of symptom-specific accommodation for the employer during the recruitment process; failing the clarification tended to lead to exaggerated conflicts in regular employees and increased resignation in non-regular employees. We identified many effective work supports and workplace accommodations to resolve or alleviate these many different difficulties that the persons experienced, focusing mainly on an appropriate job selection that allow the persons to prove themselves with reasonable working hours and sufficient holidays for fatigue recovery and health maintenance, and also on promotion of workplace accommodations for a balance between medical care and work.

(2) Discussions at the Research Committee

The research committee recognized the present new findings; the intractable diseases' characteristic symptom of "instable physical condition including general fatigability" caused a diversity of work difficulties from work preparation through a job seeking, workplace adjustment, and stable work commitment; and the effective work supports for the persons with intractable diseases should be a promotion of reasonable job selections to prove themselves and workplace accommodations for a balance between medical care and work. As summarized below, the discussions emphasized importance of effective application and dissemination of the findings to be benefitting all service providers concerning intractable diseases in health and medical, welfare and work fields.

A Characteristics of Work Difficulties due to Symptoms of Intractable Diseases

The present survey confirmed the symptom of "instable physical condition including general fatigability" as characteristic of intractable diseases, which caused a wide range of difficulties to be supported, including work performance and responsibility, a balance between medical care and work and related conflicts of relationships in a workplace, resulting in resignation and decline of self-confidence for work that in turn impeded further job seeking activities.

B Elements of Work Supports Targeting at the Work Difficulties Specific to Intractable Diseases

Work supports for persons with intractable diseases should be the real solutions for real needs based on understanding of the difficulties and problems experienced in a variety of aspects of real working life, aiming at even enrichment of their vocational life. Work problems of persons with intractable diseases are not a general consequence of all symptoms and impairments of the disease, but are very particular to the requirements and conditions of a job being sought or worked. Even the symptom of "instable physical condition including general fatigability" not necessarily prevents the persons to prove themselves as qualified workers. The comprehensive work supports have some key elements starting even before a recruitment, including assertive communication between the person and an employer about accommodations to ensure the business performance and responsibility, doctor's support on work and advice on workplace concerns, building ongoing consulting support system for both the persons and companies in need through employment period, and supporting return-to-work from both a doctor and employer's side during a sick leave.

- Placement supports for jobs that the persons can prove themselves without unreasonable overstrain
- Promotion of workplace accommodations

C Application and Dissemination of the Findings

The present new findings, identifying the work difficulties experienced in the persons with intractable diseases and the effective supports, indicate the necessity of cross-sectional supports for the persons across the fields of medical care, daily lives and work, with a viewpoint different from the conventional medical treatments or medical-oriented supports focusing on impairments in severe disabilities, thus

urge communication and training among a wide range of providers or professionals. Importantly, the findings should be disseminated by educating the general public and service providers about the chronic situation where the persons live with intractable diseases having advanced medical treatments, as well as by developing effective trainings and comprehensible information tools for the professionals in each field to serve the persons at their support needs, exercising their own expertise.

- General education for the cross-sectional supports across the fields of medical care, daily lives and work of the persons with intractable diseases
- Manuals and trainings encouraging innovative application of expertise of professionals in different fields
- Customized information provision and trainings according to types of target fields or trainees