



Research on employment difficulties for patients with intractable diseases.

(Research Report No. 172) SUMMARY

[Keyword]

Intractable Disease Patients Survey

Business Establishments Survey

Support Organizations Survey

Disability Certification

Disabilities without Certification

[Abstract]

Regarding the employment difficulties of patients with intractable diseases, the challenge is to provide the necessary employment supports to patients with intractable diseases who have employment difficulties, including those who are not covered by the disability certificate.

In this study, by conducting a survey of patients with intractable diseases, a survey of business establishments, and a survey of support organizations, we clarified the employment difficulties were caused by fragility of symptoms and/or risk of progression of intractable diseases, which are not covered by disability certification. The issues and needs for professional support at work and in the community were clarified in order for each person to find a job where he/she can play an active role with understanding and accommodation of the workplace while balancing treatment.

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2 Research period

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3 Structure of the Report

Chapter 1: Research Background, Objectives and Methodology

Chapter 2: Difficulties in Employment from the Perspective of Patients with Intractable Diseases

Chapter 3: Difficulties in Employing Patients with Intractable Diseases from the Perspective of Businesses

Chapter 4: Difficulties in Supporting Patients with Intractable Diseases from the Perspective of Support Organizations

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4 Background and Objectives of the Research

While the official disability certificate makes it easy to understand employment difficulties due to impairments, the difficulties and support needs of patients with intractable diseases who do not have the disability certificate are not easily understood by either professional supporters or people in the workplace, which may be one reason why it is difficult to actually provide reasonable accommodation and support, despite the recent development of systems and services.

In this research study, based on the basic concept of disability, by positioning the difficulty of work for patients with intractable diseases as an emerging disability due to medical advances, or as a difficulty of living due to chronic diseases, we clarified the current status and issues of support from the perspective of patients with intractable diseases, companies, support organizations, and "other physical and mental impairments" that are not included in the criteria for disability certification, which are the

causes of the difficulty of work that patients with intractable diseases actually experience.

5 Research Methodology

We conducted a comprehensive survey on the employment difficulties (difficulties in finding and keeping a job) of patients with intractable diseases, as well as the possibility of supports of companies and workplaces or community supporters, based on the framework of the International Classification of Functioning, Disability and Health (ICF). The results of the quantitative analysis of the three surveys and the qualitative information in the open comments were synthesized and reviewed by the research committee, and a comprehensive summary was made to clarify the precise understanding (assessment, etc.) of the employment difficulties of patients with intractable diseases and the ideal form of support for companies, workplaces and local communities that can be implemented in the future.

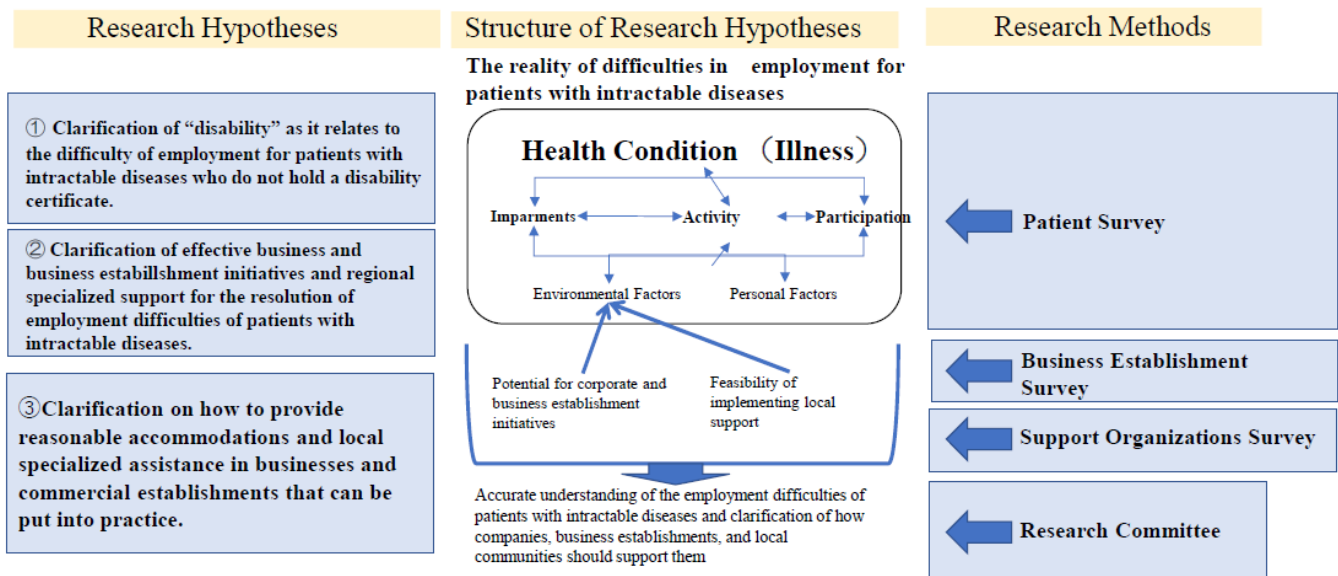


Figure 1 Research Hypotheses and Methods

- **Patients Survey:** To reach patients with intractable diseases with different characteristics between the ages of 18 and 65 nationwide, including those with minor illnesses and those with intractable diseases other than designated intractable diseases, who are important targets for verification of employment difficulties, a request was made through several support organizations with different user groups to publicize a web-based survey of patients with intractable diseases. The survey was designed to comprehensively understand the employment difficulties (difficulties in finding and keeping a job) of patients with intractable diseases as an interaction of "other physical and mental impairments" etc., environmental factors (workplace accommodation and community support) and personal factors.
- **Business establishment survey:** Regardless of the actual number of people working with intractable diseases, it is possible that many patients with intractable diseases do not disclose their intractable diseases to their workplaces. For this reason, the survey targeted 4,867 private-sector business

establishments with 10 or more employees, using the business establishment population database provided by the Statistics Bureau of the Ministry of Internal Affairs and Communications, and asked business and workplace personnel about the actual employment situation and general awareness of patients with intractable diseases, as well as to ascertain the hardship of accommodation and support at business establishments that do not understand the employment situation of patients with intractable diseases. The survey also identified the undue hardship of accommodation and support at offices that are not aware of the employment status of patients with intractable diseases.

- Support organizations survey: We surveyed 4,047 support organizations in the fields of employment support, occupational health, and health care that provide employment support to people with intractable diseases to identify the characteristics of organizations that affect the difficulty of providing support (operational readiness and readiness to meet support needs), organizational structure for employment support, characteristics of people to be supported, basic experience and knowledge, local issues of training, information provision, and regional cooperation, etc. to enable support organizations to adequately respond to the employment support needs of people with intractable diseases.
- Research Committee: Information was exchanged among patients with intractable diseases, related support organizations and administrative officials, experts, and others to understand the employment difficulties of patients with intractable diseases, their employment support needs, the status of employment support in the community and workplace, and to organize employment support issues for patients with intractable diseases.

6 Details of the Research

(1) Patient survey

a. Status of survey responses

Responses were obtained from 4,523 persons with intractable diseases. Although the situation varied greatly depending on disease, sex, age, and other factors, 70% of the respondents were employed, and 75.4% (3,410 persons) had not applied for a disability certificate.

b. Relationship between "other mental and physical impairments" and employment difficulties for people with intractable diseases

More than half of the respondents with intractable diseases with "other physical and mental impairments" etc. had difficulties in social life, and even among those who had not applied for a disability certificate, 44% had considerable difficulties in social life and 76% had more than slight difficulties.

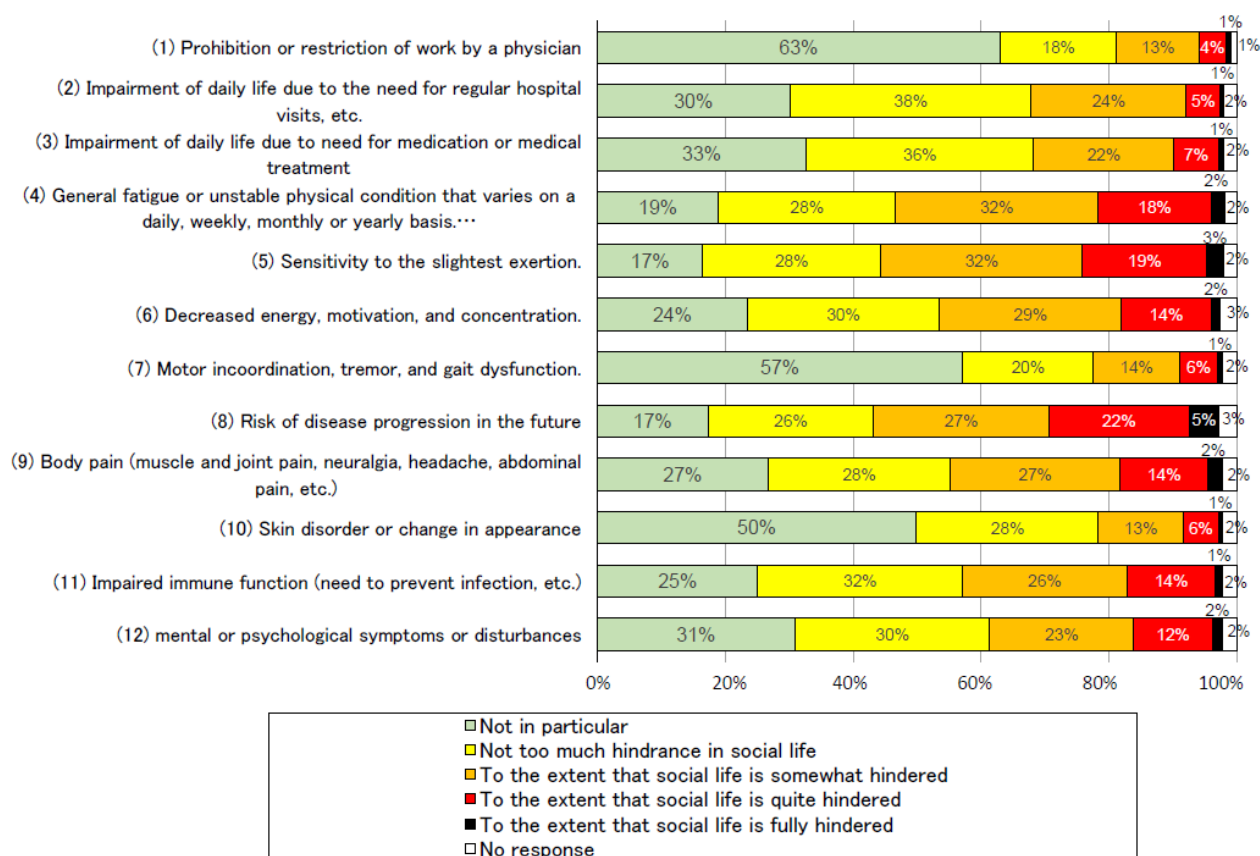


Figure 2: Experiences of Social Life Barriers Due to Various "Other Physical and Mental Functioning Impairments" Among Patients with Intractable Diseases
(Those who have not applied for a disability certificate n=3,410)

Among the "other physical and mental impairments" etc. that are not included in the criteria for disability certification (listed in order of most significant social life difficulties), the following were found to be related to employment difficulties at various stages of employment.

- Risk of disease progression: uncertainty about the future due to the uncertainty of the disease, difficulty in performing duties and scheduling work as the disease worsens, including physical instability, and increased worry about future job prospects while undergoing treatment and social alienation in a situation where paid leave is scarce.
- Physical fragility at the slightest exertion: The ease with which one's physical condition can deteriorate is difficult to be understood, and as disabilities increase, full-time work and overtime are perceived as burdensome, increasing the risk of leaving job due to difficulties in adapting to work and an increase in sudden absences from work.
- Generalized fatigue and changes in physical condition: fatigue and other symptoms that are difficult to see from the outside, and as the disorder worsens, the patient has limited time to concentrate on work, frequent hospital visits and absences, and lack of understanding at work, making it difficult to maintain stable employment.
- Decreased vitality and concentration: easily misinterpreted as lack of motivation, increased stress in work relationships, increased difficulty working full time and performing tasks as the level of

disability increases and increased social alienation.

- Physical pain: Increased disability due to joint pain and headaches throughout the body makes daily life and work difficult, and is aggravated by work, stress, etc., but it is difficult to explain and gain understanding of the condition.
- Decreased immune function: difficulty in getting around and work restrictions in the medical profession; increased disability leads to increased susceptibility to colds and infections, work restrictions, and frequent absences, making it difficult to continue working.
- Mental and psychological symptoms (including secondary disorders): not only are developmental and other disorders related to work performance and communication in the workplace, but also stress in the workplace and/or difficulties in finding employment lead to mental deterioration.
- Necessity of regular hospital visits: Increased disability increases work restrictions and psychological distress due to physical condition management, etc.
- Need for medication and treatment: Medication side effects, changes in physical condition, and the need for medication adjustments are difficult for those around them to understand, and increasing barriers limit their employment options and make it difficult for them to continue working.
- Impairment of motor coordination and gait function: affects job performance, etc., and in severe cases, difficulty in walking and maintaining a sitting position.
- Skin disorders and changes in appearance: discriminatory attitudes and lack of understanding of the environment in interpersonal relationships and customer service are problems.
- Restrictions on work by doctors: Work is restricted according to symptoms, and in the most severe cases, work is considered impossible.

c. Environmental factors (workplace considerations, community support) and individual factors related to the difficulty of employment for patients with intractable diseases.

(a) Relationship between workplace accommodation and employment difficulties

Although it was considered necessary for companies and workplaces to have in place job descriptions, working hours, and holidays that facilitate hospital visits, health management, and breaks, as well as correct understanding of illness and disability by superiors and co-workers, all of which are related to preventing and solving problems related to employment difficulties, many of the actual implementation rates were less than half of those of the patients with intractable diseases. Although patients with intractable diseases can perform a variety of jobs and work longer hours depending on the degree of stability of their physical condition, it has been observed that they tend to be limited to less strenuous jobs and shorter working hours due to their unstable physical condition. Disclosure to the workplace was timed at the time of employment or after employment, depending on the need for understanding and accommodation of the workplace and support, while avoiding misunderstanding, discrimination, unnecessary worry or overreaction. However, there were some situations where the inability to disclose appropriately made treatment or medication difficult, etc.

(b) Relationship between utilization of community support, etc. and employment difficulties

Regardless of the status of their disability certificate, patients with intractable diseases need vocational guidance and job placement, workplace understanding and accommodation, and ongoing support for themselves and their workplace to cope with worsening of their disease or progression of their disability after employment, in order to find a job where they can play an active role and live the professional life they want as much as possible, with workplace understanding and accommodation, while balancing their hospital visits and treatment. They also called for improved social support through comprehensive coordination of support systems and services for treatment, daily living, and employment. The sources of employment counseling included family and specialist doctors, friends and family, Hello Work (Public Employment Supports Office), Intractable Disease Consultation Support Centers, and staff of medical institutions, etc. However, in reality, many of them did not know how to use local specialized supports, although the use was related to the prevention of many employment difficulties and the solution of problems. There was also a situation in which specialized supports were not effectively used by patients with intractable diseases who did not have a disability certificate.

(c) Relationship between individual factors and employment difficulties of patients with intractable diseases

It was found that the degree of employment difficulties among patients with intractable diseases is influenced to a certain extent by gender and age, and that patients with intractable diseases who actively pursued economic independence and quality of life experienced more difficulties in employment. On the other hand, it was found that the situation in which the patient "thinks he/she can find a solution to the difficulties and problems that arise in daily life" is not only related to the prevention and solution of many employment difficulties, but is also strongly related to the stabilization of physical condition and the reduction of obstacles in social life.

(2) Business establishments survey

a. Status of survey responses

Of the 4,867 establishments, 758 responded (15.6% response rate).

b. Issues in understanding the support needs of employees with intractable diseases and providing support

Regarding the employment of workers with intractable diseases, more than 60% of the enterprises reported that they had no experience in employing such workers. It was also clear that although the employment status of persons with disabilities and the status of employees on leave were understood, the employment status of employees with intractable diseases was not easily understood. The most common reason for enterprises to identify employees with intractable diseases were at the request of the employees themselves, due to the need for regular hospital visits, work accommodations, support in

balancing treatment and work, leave of absence, and other needs.

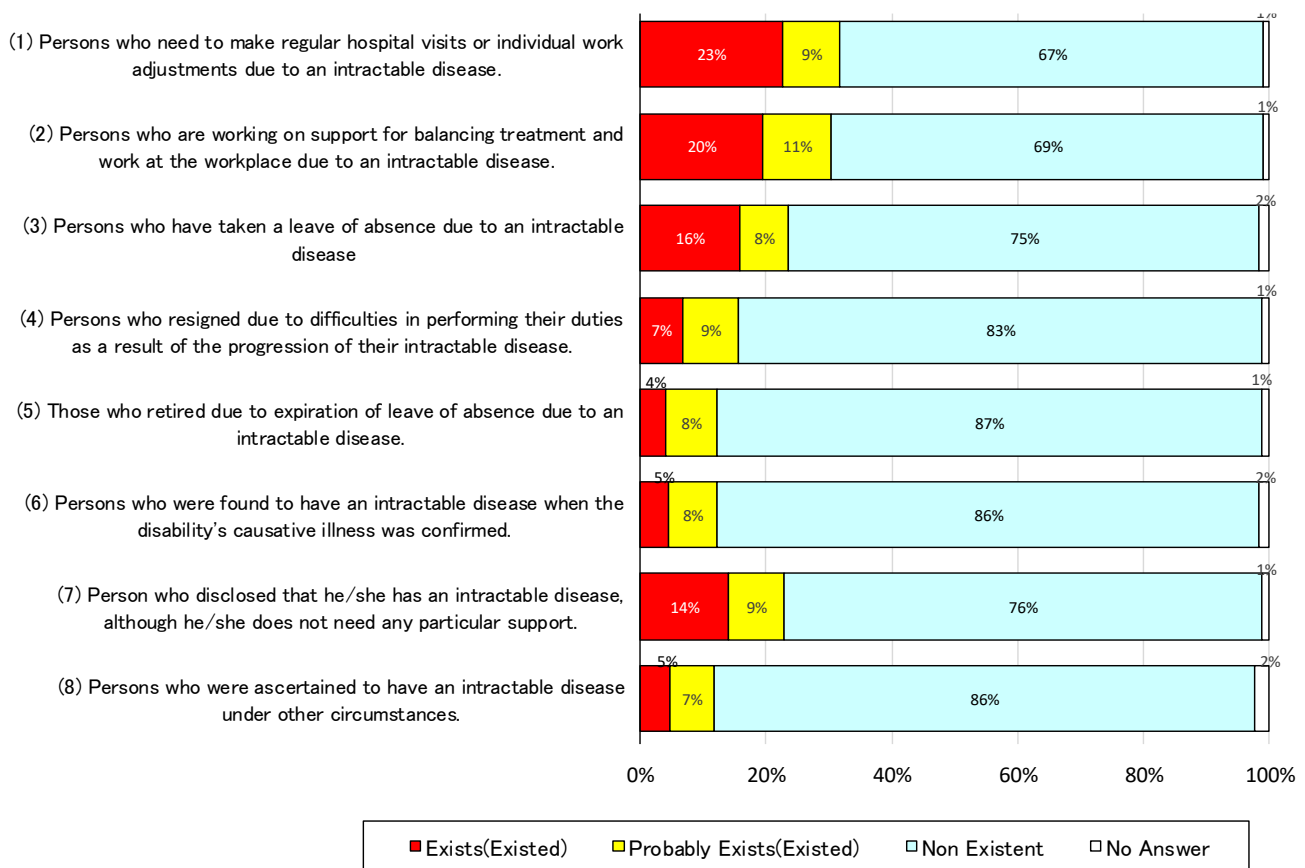


Figure 3: Perceived Experience of Employing Employees with Intractable Diseases at Businesses establishments (n=758)

c. Issues in promoting understanding of support needs of employees with intractable diseases in companies and implementation of support and consideration.

Among business establishments with experience in employing people with intractable diseases, the following support and considerations were identified as necessary but not often implemented or too burdensome: promoting understanding through information and training on disability and intractable diseases, career planning with an eye on the progression of the disease, etc.

On the other hand, those establishments with no experience in employing people with intractable diseases showed a general lack of information and knowledge about work and work styles that are comfortable for people with intractable diseases, recognition of support needs due to changes in physical condition, and knowledge and information about the obligation to provide reasonable accommodation, etc. Although there are cases in which establishments with a small number of employees tend to lack knowledge and information about the symptoms and working styles of patients with intractable diseases because they do not know the experience of employing employees with intractable diseases, they are not subject to the statutory employment quota system for persons with disabilities, they are not required to appoint an occupational physician, etc., it is also suggested that even small establishments can obtain

information and knowledge about intractable diseases through their actual experience of employing employees with intractable diseases.

(3) Supporting organizations survey

a. Status of survey responses

There were 537 responses (13.3% response rate), with labor transition support offices receiving the largest number of responses (181), followed by Hello Work and employment supporters for patients with intractable diseases (104), health centers (103), and others.

b. Status of support for patients with intractable diseases at support organizations

The frequency of opportunities to deal with patients with intractable diseases in their daily work was generally low for the responding institutions as a whole, and by support organization, the Intractable Disease Consultation Support Center had relatively more opportunities to deal with all patients with intractable diseases except "patients with intractable diseases who have continuous and advanced support needs for medical care and daily life, such as total paralysis and use of ventilators" and the Intractable Disease Consultation Support Center. Hello Work provided a wide range of employment support for patients with intractable diseases other than those with serious illnesses, while the Comprehensive Support Center for Occupational Health, the Employment and Living Support Center for Persons with Disabilities, and the Work Transition Support Offices had relatively little involvement with patients with intractable diseases.

Regarding the positioning of employment support for persons with intractable diseases in their work, many respondents at Hello Work and Counseling Support Centers for Persons with Intractable Diseases answered that "there is a clear positioning and awareness in their work", while there were fewer respondents at Public Health Centers and Work Transition Support Offices. In employment and livelihood support centers for persons with disabilities, many respondents answered that "there is some degree of positioning or awareness of the issue in their work."

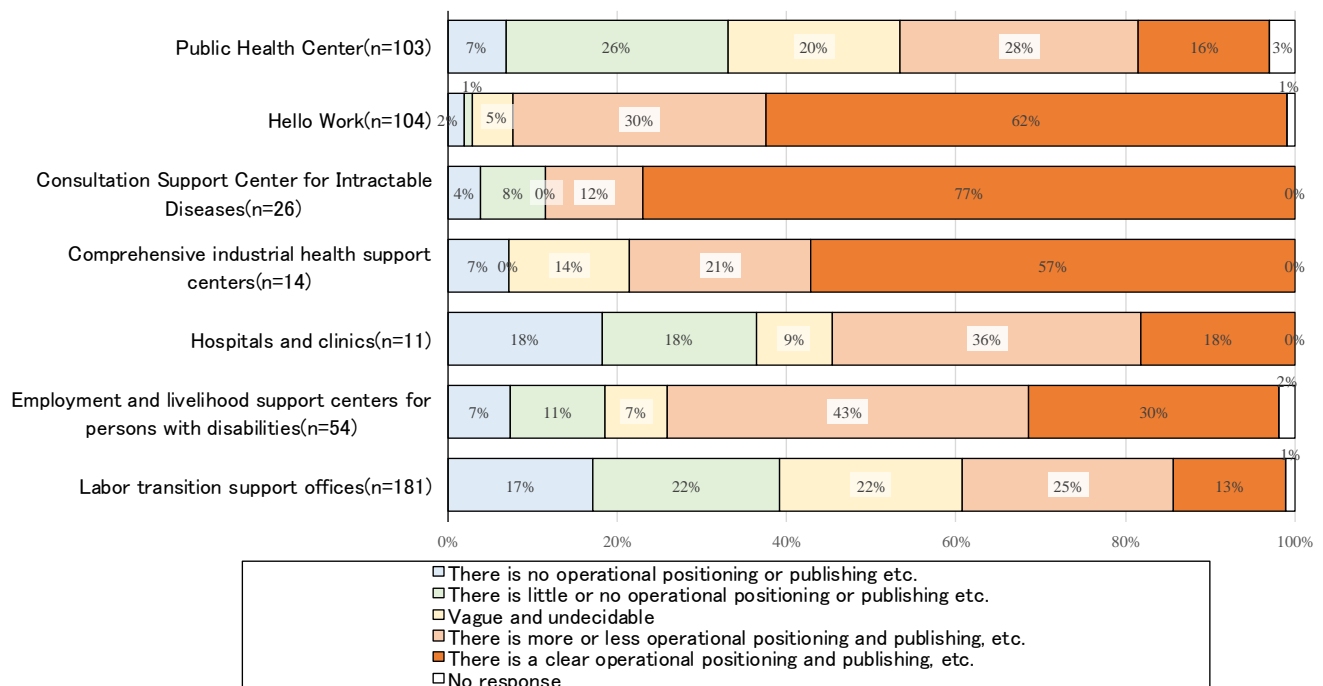


Figure 4 Status of positioning of in the work of employment support for patients with intractable diseases in support organizations, and the status of publicizing this information to related organizations, etc.

c. Specific difficulties in supporting patients with intractable diseases in support organizations

The situation of support difficulties at the supporting institutions varied from institution to institution, but in general, the following situations were found.

- Lack of awareness of the actual situation of patients with intractable diseases in daily work and support: Items that generally received few "strongly agree" responses in daily work included: "Many patients do not consider themselves "disabled" according to their illness", "Many patients work at desk jobs or part-time", "Many patients work without explaining their illness at their workplace", and "Even the most severely ill patients are increasingly seeking employment due to advances in IT." etc. There was also little recognition of "the importance of job placement assistance, taking into account the duration of unemployment benefits and the economic situation of each patient". On the other hand, "strong awareness" of the "importance of understanding and accommodating hospital visits and physical condition management in the workplace" and "importance of continuing to balance treatment and work not only after finding a job, but also after finding a job" were the most common items of support.
- Difficulties in daily case management: Efforts that were generally less involved included "improving life functioning by improving the environment and interpersonal support" and "assessment and support in actual life situations such as home, community, and work.
- Issues in multidisciplinary collaboration: In the Employment and Living Support Centers for Persons with Disabilities and the Work Transition Support Offices, awareness of the systems and services

stipulated in the Law on Comprehensive Support for Persons with Disabilities and the Law on Medical Care for Patients with Intractable Diseases was low, while in the health care field, awareness of the systems and services, etc. stipulated in the Law on Employment Promotion for Persons with Disabilities and the Law on Comprehensive Support for Persons with Disabilities tended to be low.

- Lack of utilization of information: The percentage of respondents using various manuals, booklets, etc. was low, except for the Intractable Disease Consultation Support Center and Hello Work, which are clearly positioned in their work to support the employment of patients with intractable diseases. The use of information at work transition support offices was noticeably low for all responding organizations.
- Other issues: Other issues included small number of patient users related to employment support and a lack of knowledge and skills in support. The company considered it necessary to promote companies' understanding of patients with intractable diseases and to expand systems that enable patients with intractable diseases to continue working.

d. Employment support considered appropriate for patients with intractable diseases.

The most common responses were "understanding and accommodation in workplaces where it is easy to work while balancing treatment", "securing jobs where one can play an active role while balancing treatment", "support for continued employment during the progression of illnesses and disabilities", "improving specialized employment support services", "increasing welfare-type employment and very short hours", and "improving workplace facilities, assistive technology, teleworking, etc.".

(4) Discussions and considerations by the Research Committee

In this research, we specifically clarified the employment difficulties and employment support needs of patients with intractable diseases. Among them, we clarified the relationship between the specific content and degree of "other physical and mental functional impairments", which are not included in the traditional disability certification criteria, and employment difficulties.

In addition, although patients with intractable diseases are subject to the prohibition of discrimination against persons with disabilities and the obligation to provide reasonable accommodation regardless of whether they have a disability certificate or not, in actual workplaces there is a lack of awareness of employment support for patients with intractable diseases, and specific efforts have not progressed. Therefore, it is necessary to further promote the employment of people with intractable diseases, prohibit discrimination and provide reasonable accommodation for them, considering the burden on companies.

Furthermore, although various training programs and information have been provided for local professional support organizations and professional supporters, there are cases where the support needs of patients with intractable diseases are not fully recognized, and there are situations where the support needs of patients with intractable diseases without a disability certificate and the comprehensive support needs of medical care, daily life, and employment are not effectively implemented.

7 Relevant research products

- Study on the Actual Situation of Difficulty in Employment According to the Degree of Symptoms of Intractable Diseases and the Way of Employment Support, Research Report №126, 2015.
- Research and Study on Dissemination and Improvement of Manuals Contributing to Employment Management of Persons with Incurable Diseases, Research Report №141, 2018
- Actual conditions and issues of support for employment and workplace settlement of patients with intractable diseases through cooperation between companies and local organizations and occupations, Research Report №155, 2021