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Perceptions regarding a range of work-related issues and corresponding support needs of individuals with an intractable disease

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Summary **A number of persons with an intractable disease (ID) experience work-related problems that could lead to job loss. The aim of this study was to ascertain perceptions regarding a range of work-related issues and corresponding support needs of individuals with an ID. Potential participants were people ages 15 to 64 with one of the 130 intractable chronic diseases designated in the Act to Comprehensively Support the Daily and Social Activities of Persons with Disabilities (Comprehensive Support for the Disabled Act). Participants completed a self-administered questionnaire. With the assistance of patients' organizations, 3,000 questionnaires were mailed to potential participants. Questions included demographic characteristics, family concerns, employment/supported employment, work accommodations, and other aspects of life. Responses were received from 889 (29.6%) participants, and respondents had 57 IDs. Forty-six-point-seven percent of respondents reported being unemployed due to fatigue and/or long-term treatment. Nearly half of the unemployed respondents reported that they had been unable to work despite their willingness to do so. Common requests for accommodation included flexible work hours, working at home, and job/workplace modifications. Only 30% of respondents knew about job training programs and supported work available for persons with disabilities. The results of the study are relevant for employees, employers, and occupational health/human resource professionals. The issue of reasonable accommodations for persons with an ID needs to be addressed in future research in order to promote continued work by those persons.**

Keywords: Intractable disease, chronic disease, employment, supported, social welfare

1. Introduction

Intractable diseases (IDs) are defined in the Principles of Policy for Intractable Diseases issued in 1972 by the Ministry of Health, Labour, and Welfare of Japan as: *i*) diseases that have resulted from an unidentifiable cause and, without a clearly established treatment, have a considerably high risk of disability, or *ii*) diseases that chronically develop and that require a significant amount of patient care, causing a heavy burden on their family members both financially and mentally. Some of the characteristic problems of IDs include development of multiple disorders in addition to the main symptoms of a specific ID (*1,2*), an unstable general condition as symptoms worsen over several years, and variance in symptoms depending on patient's physical condition

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on a given day as well as the medication the patient is taking (*3,4*). In addition to these problems, some patients have symptoms that preclude them from living a regular life, such as fatigue (*5,6*), pain (*7*), and diarrhea (*8*). That said, many IDs have become chronic but manageable conditions because of advances in treatment, rehabilitation, and preventive medicine.

The needs of patients with an ID vary significantly since their treatments continue for years and their physical and mental status changes with age. These patients' need for employment has become an important issue in recent years (*9*) since patients need to lead a life with dignity in the community (*10*). Employment support (ES), including support provided *via* social welfare services, has therefore become an urgent issue for Japan to address.

An ES system for patients with an ID in Japan has yet to be fully implemented (*11*), but patients with an ID are clearly categorized as persons with a disability under the Act to Comprehensively Support the Daily and Social Activities of Persons with Disabilities (Comprehensive Support for the Disabled Act), which was implemented in 2013. People who use welfare services will now presumably increase. In 2013, a study examined the use of employment-related welfare services (EWS) by persons with an ID in Japan (*12*). Major findings of that study were that ES services under the Comprehensive Support for the Disabled Act had not adequately reached the public and that only 16% of service providers had provided services to patients with an ID. However, patients, *i.e.* users of those services, were not included in that study, so those findings only depict part of the situation. The current study should be able to depict the rest of the situation. As a complement to the previous study, the current study has sought to ascertain perceptions regarding a range of work-related issues and corresponding support needs of individuals with an ID.

2. Materials and Methods

Potential participants in this study were patients with one of the 130 intractable chronic diseases (Supplementary Table S1, *http://www.irdrjournal.com/docindex.php?year=2016&kanno=3*) designated in the Comprehensive Support for the Disabled Act. According to the Act, the 130 designated chronic diseases must meet 3 requirements: the lack of an established cure, the need for long-term treatment, and the existence of diagnostic criteria. Therefore, an intractable chronic disease may not necessarily be a rare disease. Since this study focused on work-related issues, potential participants were patients between the ages of 15 and 64, the legal working age and the general retirement age in Japan, respectively.

Potential participants were sent an anonymous self-administered questionnaire. The participants were provided with instructions that including the following: an explanation of this study and its purpose, contact information, a statement on anonymity and confidentiality, and a note indicating that returning the questionnaire by mail would constitute consent to participation in this study. The questionnaire asked participants to report their status as of Oct 1, 2014. Since the mailing addresses of patients are nonpublic personal information, prefectural patients' associations were asked for their cooperation. These associations are organized by region, not by disease type. With the assistance of those patients' associations, 3,000 questionnaires were mailed. The questionnaire included questions regarding demographic characteristics, family concerns, employment/supported employment, work accommodations, and other aspects of life.

The Ethics Committee of the National Rehabilitation Center for Persons with Disabilities approved this study.

3. Results

3.1. *Demographic data*

Responses were received from 889 (29.6%) participants with 57 IDs (Table 1) living in 41 of 47 prefectures in Japan. The most frequently reported diseases were connective tissue diseases such as systemic lupus erythematosus and takayasu arteritis, followed by nervous system disorders such as Parkinson's disease and myasthenia gravis, digestive system disorders such as Crohn's disease and ulcerative colitis, and visual disorders such as retinitis pigmentosa. The demographic characteristics of respondents are shown in Table 2.

3.2. *Employment status*

Of the 889 respondents, 459 (51.6%) reported that they were employed, 415 (46.7%) were unemployed, and 15 (1.7%) were did not respond. The most frequently reported reasons for unemployment were "physical decline" such as fatigue, mobility problems, and "Time commitments for treatment" such as long-term treatment and frequent hospital appointments (Table 3A).

Asked about their willingness to work (Table 3B), over half (56.6%) of the respondents who reported that they were "unemployed" also reported that they had been "unable to work despite [their] willingness to do so." Typical comments included "I want get a job when my physical strength has improved," "I would like to consider getting a job when my systemic pain is relieved," and "I would like to work at home so I can work at my own pace."

Common requests for accommodation included flexible working hours, working at home, and job/workplace modifications. The most common needs at work (Table 3C) were "a workplace that understands my condition" and "employment support." Furthermore, many of the comments on needs at work concerned working/the workplace such as "working conditions

Table 1. The number of respondents and percentage of 889 participants with 57 intractable chronic diseases

Diseases	Number of respondents	%
Systemic lupus erythematosus	195	21.9
Parkinson's disease	101	11.4
Myasthenia gravis	81	9.1
Takayasu arteritis	80	9.0
Sjogren's syndrome	63	7.1
Malignant rheumatoid arthritis (rheumatoid vasculitis)	56	6.3
Retinitis pigmentosa	48	5.4
Spinocerebellar degeneration	44	4.9
Polymyositis-dermatomyositis	35	3.9
Multiple sclerosis	29	3.3
Mixed connective-tissue disease	29	3.3
Ulcerative colitis	23	2.6
Scleroderma, dermatomyositis, or polymyositis	22	2.5
Crohn's disease	20	2.2
Behcet's disease	16	1.8
Ossification of the posterior longitudinal ligament	13	1.5
Periarteritis nodosa	11	1.2
Antiphospholipid syndrome	11	1.2
Moyamoya disease	9	1.0
Chronic inflammatory demyelinating polyneuropathy	9	1.0
Adult-onset Still's disease	7	0.8
Primary pulmonary hypertension	7	0.8
Allergic granulomatous angiitis	5	0.6
Idiopathic chronic pulmonary thromboembolism with pulmonary hypertension	5	0.6
Idiopathic necrosis of the femoral head	4	0.4
Idiopathic osteonecrosis of femoral head	4	0.4
Ossification of the ligamentum flavum	3	0.3
Primary biliary cirrhosis	3	0.3
Hypopituitarism	3	0.3
Shy-Drager syndrome	2	0.2
Amyotrophic lateral sclerosis	2	0.2
Syringomyelia	2	0.2
Striatonigral degeneration	2	0.2
Aplastic anemia	2	0.2
Mitochondrial disease	2	0.2
Autoimmune hepatitis	2	0.2
Wegener's granulomatosis	2	0.2
HTLV-1-associated myelopathy	2	0.2
Guillain-Barré syndrome	1	0.1
Spinal muscular atrophy	1	0.1
Spinal and bulbar muscular atrophy	1	0.1
Lysosomal storage diseases	1	0.1
Subacute sclerosing panencephalitis	1	0.1
Ossification of the anterior longitudinal ligament	1	0.1
Age-related macular degeneration	1	0.1
Sudden sensorineural hearing loss	1	0.1
Idiopathic bilateral sensorineural hearing loss	1	0.1
Syndrome of abnormal secretion of prolactin	1	0.1
Syndrome of abnormal secretion of antidiuretic hormone	1	0.1
Addison's disease	1	0.1
IgA nephropathy	1	0.1
Refractory nephrotic syndrome	1	0.1
Dilated cardiomyopathy, congestive cardiomyopathy	1	0.1
Severe acute pancreatitis	1	0.1
Neurofibromatosis type 1	1	0.1
Neurofibromatosis type 2	1	0.1
Epidermolysis bullosa	1	0.1

where I can feel free to request a short break when I don't feel well," "a workplace where a protocol is in place in case I unexpectedly fall sick," and "I am hesitant to use employment support services because coworkers might begin to resent my occasionally taking time off for treatment and doctor's visits."

3.3. *Awareness of employment-related welfare services (EWS)*

Providers of EWS offer transition support, *i.e.* job training/placement, or continued support, *i.e.* job opportunities, for persons with a disability in Japan. Of 889 respondents, 260 (29.2%) reported that they knew of EWS while 611 (68.7%) reported that they have never heard of EWS (Table 4A). Approximately 20% of the respondents who reported that they had "never heard of EWS" were asked if they wanted to know about those services but responded that they had "no need" or "no opinion" (Table 4B). In contrast, more than half of the respondents had a favorable view of EWS. Typical comments were that "Although I don't intend to get a job,

Table 2. Demographics and baseline characteristics of 889 respondents

Characteristics	*n* = 889	%
Age (mean: 49.5, S.D.: 10.7)		
Sex		
Male	249	28.0
Female	635	71.4
N/A	5	0.6
Families and Living Arrangements (multiple answers allowed)		
living alone	121	13.6
living with spouse or partner	490	55.1
living with parents	265	29.8
living with children, and children-in-law	265	29.8
living with siblings	62	7.0
living with grandparents	18	2.0
living with grandchildren	15	1.7
living with others	31	3.5
Primary caregivers (multiple answers allowed)		
living independently	555	62.4
spouse or partner	172	19.3
parents	87	9.8
children, and children-in-law	33	3.7
siblings	20	2.2
grandparents	1	0.1
grandchildren	0	0.0
home care services (public)	57	6.4
home care services (private)	15	1.7
other	30	3.4
there is no one to ask for help	16	1.8
Ability to go out (multiple answers allowed)		
able to go out alone	736	82.8
need an attendant	145	16.3
need to be dropped off and picked up	104	11.7
other	40	4.5
Current residence		
self/family-owned housing	686	77.2
rented public/private housing	176	19.8
housing for company/government employees	14	1.6
hospital	2	0.2
group home/welfare facility	1	0.1
other	6	0.7
no response	4	0.4
Primary source of income (multiple answers allowed)		
salary, wages, or fees for labor	454	51.1
pension	285	32.1
benefits	47	5.3
welfare payment	24	2.7
allowance from family	20	2.2
business/assets	40	4.5
other	156	17.5

knowing about those services is a good thing," "I don't need the information at this moment, but I may want it if I need it in the future," and "I want to use EWS to find out how long I can work and how much work I can manage."

4. Discussion

This study analyzed 889 responses from individuals with an ID. Responses were collected from patients with 57 different diseases out of designated 130 IDs. To survey patients with the remaining 73 diseases,

Table 3. Reasons for unemployment (A), willingness to work (B), and needs at work (C) among 415 respondents who answered that they were "unemployed"

(A) Response	*n* = 415*	%
Physical decline	219	52.8
Time commitments for treatment	151	36.4
Unable to find a right job	107	25.8
Concentrating on studying/housekeeping	102	24.6
No need to work	46	11.1
Need ongoing care	39	9.4
Aged	35	8.4
Other	74	17.8

*Multiple answers allowed.

(B) Response	*n* = 415*	%
I am unable to work despite my willingness to do so	235	56.6
I don't want to work/I don't need to work	78	18.8
I am seeking a job	44	10.6
Other	25	6.0
No response	33	8.0

(C) Response	*n* = 415*	%
A workplace that understands my condition: Exemption from physically demanding tasks such as handling heavy objects and after-hours work	232	56
Employment support: Support to find a job that meets my requirements or employers/co-workers are informed about my condition	193	47
Flexible work hours and break time: Permission to adjust work hours, Time off for hospital appointments or care	166	40
Right career/Rewarding career	118	28
Telecommuting	111	27
Barrier-free workplace	87	21
Assistance with travel to work	77	19
Inclusion in the employment quota system	54	13
Work-sharing	44	11
Attendant care in the workplace: suction	17	4
Self-care accommodations in the workplace: stoma care	10	2
Other	20	5

*Multiple answers allowed.

Table 4. Awareness of employment-related welfare services (EWS) among 889 participants (A), and the desire to know about EWS among 611 respondents who answered that "I've never heard of EWS" (B)

(A) Response	*n* = 889	%
I knew of EWS	260	29.2
I've never heard of EWS	611	68.7
No response	18	2.0

(B) Response	*n* = 611	%
I want to know about those services	341	55.8
No need	130	21.3
No opinion	120	19.6
Other	9	1.5
No response	9	1.5

other questionnaire distribution channels, such medical institutions or academic societies, need to be explored separately. According to representatives of some of the patients' associations, lists of patients' mailing addresses do usually not include patient ages, so the questionnaire could have been unintentionally mailed to patients outside the targeted age range, thus leading to the low response rate.

Approximately half of the respondents were employed at the time of the survey, and half of the unemployed respondents reported difficulties in getting a job despite their willingness to work. The main reasons for their unemployment were "physical decline" and "time commitments for treatment." Analysis of the reasons for unemployment indicated that some of the respondents' perceptions stemmed from a lack of information on the support services available to them. Respondents reported several areas where they desired special accommodations, such as working hours, job tasks, the workplace, and time off for hospital visits/care. These areas coincided with the areas where providers of EWS made special arrangements, as indicated by the survey of those providers in 2013 (*12*).

Results of the current survey indicated that awareness of EWS is as low as 30%, and respondents were also not sufficiently aware of general welfare services for the disabled, either. Since half of the respondents who had been unaware of those services reported that they wanted to know more about those services, medical/welfare institutions need to have a system that reliably informs patients of available welfare services during their diagnosis and treatment.

Detailed interviews need to be conducted to ascertain the needs of individuals with an ID and the accommodations that providers of EWS actually make in order to recommend what welfare services individuals with an ID need to facilitate their employment in Japan.

In conclusion, an understanding of the perceptions regarding work-related issues and the corresponding support needs of patients with an ID is essential not only for people providing support but for all relevant parties. The results of this study, therefore, are relevant for employees, employers, and occupational health/human resource professionals. Placing an excessive burden on co-workers and employers would result in the loss of employment opportunities for patients with an ID. Thus, the issue of reasonable accommodations for persons with an ID needs to be addressed in future research in order to promote continued work by those persons.

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